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GENETIC COUNSELING IN MILITARY HOSPITALS

A Thesis

Presented to

The Judge Advocate General's School, United States Army

The opinions and conclusion expressed herein are those of the author and do not necessarily represent the views of either The Judge Advocate General's School, The United States Army, or any other governmental agency.

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35TH JUDGE ADVOCATE OFFICER GRADUATE COURSE

April 1987

GENETIC COUNSELING IN MILITARY HOSPITALS

by Major Philip H. Lynch

ABSTRACT: This thesis examines genetic counseling in military hospitals. With the rapid development of claims for wrongful life and wrongful birth and improved in-utero diagnostic techniques, military physicians face increased responsibilities in the performance of genetic counseling for military families. This thesis concludes that military physicians have generally met the standards of care for genetic counseling, but increased funding for personnel and equipment is necessary for military physicians to adequately perform genetic counseling.

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Staff Sergeant John Smith is stationed at Fort Black, California. His 34 year old wife, Judy Smith recently gave birth to their first child. Mrs. Smith was treated for her pregnancy at Ford Army Hospital at Fort Black. During her first appointment, Mrs. Smith told her obstetrician that she was in good health and exercised regularly. She revealed that she had been a frequent drug user during high school and college. Mrs. Smith told her physician she had miscarriages when she was twenty-four, twenty-six, and twenty-seven. After a normal and uncomplicated pregnancy, Mrs. Smith delivered a 7 pound 10 ounce girl. Unfortunately, the baby was born with a genetic defect, a mild form of spina bifida.¹ This genetic injury paralyzed her legs. The treating pediatricians told the Smiths that in the future, their daughter, Sara, could also suffer from mental retardation and lack of bowel and bladder control and that she would require extensive therapy and rehabilitation at a local civilian medical center. The Smiths learned that their daughter would require a special bed and they would have to modify their house to accommodate their daughter's wheel chair.

The treating physicians told the Smiths that Civilian Health and Medical Program of the Uniform Services (hereinafter CHAMPUS) would not pay the total cost of Sara's medical care. The Smiths then met with a civilian attorney who specialized in filing claims against the United States under the Federal Tort Claims Act.² The Smiths' attorney filed a five million dollar administrative claim on behalf of Staff Sergeant and Mrs. Smith for the wrongful birth of their daughter, and a five million dollar wrongful life claim on behalf of Sara. The Smiths alleged that the physicians at Ford Army Hospital were negligent in failing to conduct genetic counseling or to refer the Smiths to a genetic counselor. The Smiths also alleged the treating physicians failed to perform alpha-fetoprotein (hereinafter AFP) testing³ on Mrs. Smith during her pregnancy and failed to offer the Smiths the opportunity to undergo amniocentesis.⁴

After six months of unsuccessful negotiations with attorneys from the U.S. Army Claims Service, the Smiths filed suit in United States Federal District Court. Following a four day trial the judge ruled the Army physicians had been negligent in failing to conduct genetic counseling and negligent in failing to offer AFP testing or amniocentesis. The court held that wrongful life and wrongful birth suits were cognizable in California and awarded the Smiths a total of six million dollars. The bulk of the award compensated the Smiths for the costs of providing custodial care for Sara throughout her life.

I. INTRODUCTION

The above-described scenario involving a hypothetical soldier and his wife could occur at any military hospital. This article will discuss the issues raised by the birth of Sara Smith. Prospective parents in the United States have benefited from the improved information available to diagnose human genetic disorders.⁵ Sergeant and Mrs. Smith's successful suit is a reflection of the new requirements for genetic counseling.

Military physicians, as well as their civilian peers, have had to adjust to rapid changes in the standard of care for genetic counseling. Military physicians must decide if genetic counseling is necessary during the treatment of each prospective mother. Once a physician decides genetic counseling is necessary he must decide which diagnostic tests are appropriate. This process is necessary to provide parents like Sergeant and Mrs. Smith with information about their unborn children to allow them to make informed decisions about their reproductive choices.

Since the first reported analysis of fetal cells from amniotic fluid in 1966,⁶ parents have been given increasingly sophisticated information about prenatal genetic disorders. Twenty percent of infant deaths are caused by genetic disorders. Genetic disorders are estimated to be the

second leading cause of death for one to four year olds.⁷ Given these statistics, parents are understandably interested in obtaining information about their unborn children. Once parents have learned that their fetus has a genetic disorder they face the difficult decision of whether to abort the unborn child. The parents must grapple with the emotional issues involved with abortion as well as making a medical decision.

As technology has been able to diagnose an increasing number of prenatal genetic disorders, there has been a corresponding increase in the number of suits involving the alleged negligence of a physician in failing to advise, counsel, and test the parents of a fetus with a possible genetic disorder suggested by family history, maternal age, or prolonged drug use. The claim of the parents in this instance is commonly called a suit for wrongful birth.⁸ The claim of the child is for wrongful life with the child arguing that he would have been better off unborn than alive in his handicapped state.⁹

Doctors in Army, Navy, and Air Force hospitals deliver a large number of infants due to the relatively young age of American military personnel. The vast majority of soldiers, sailors, and airmen and their spouses are between the ages of eighteen and forty-two. Therefore, most military careerists have their children in military hospitals. Military families have filed administrative claims under the Federal Tort Claims Act (FTCA)¹⁰ for wrongful life and wrongful birth claims within the United States.¹¹ Several plaintiffs have prevailed in suits against the United States under theories of wrongful life and wrongful birth.¹² As the number of genetic disorders which can be diagnosed in-utero increases, the number of suits alleging negligent genetic counseling will increase. A claim or lawsuit involving negligent genetic counseling often results in a damage award to compensate parents and a child for the costs of care and rehabilitation. Courts have awarded substantial amounts for general and special damages.¹³

Military physicians face difficult challenges in providing genetic information to their patients while the medical research community is continually updating the number of genetic diseases which can be diagnosed in-utero. Military physicians treat pregnant women in a socialized medicine setting with large numbers of patients. Physicians in military hospitals often do not follow the same women patients throughout their pregnancies, but are assigned to clinics where they examine patients on a first come-first served basis. This system limits personal communications between physicians and patients which often effects the physician's opportunity to discuss matters of concern, including genetic counseling, with their patients. Since genetic counseling involves the exchange of information between patient and physician, the military system is less than ideal for the performance of genetic counseling.

Another important feature of the military medical care system is that military hospitals are a small part of a large organization tasked with defending the United States. Funding for military hospitals for both personnel and equipment has often been sacrificed in the competition for defense budget dollars. The diagnostic testing which is an integral part of genetic counseling requires the purchase of sophisticated medical equipment as well as facilities for laboratory testing. More genetic counselors are often necessary to provide information to patients on the increased level of genetic data available as a result of data provided by laboratory and diagnostic tests.

My purpose in writing this article is to clarify the legal issues which may arise in the military health care system when families such as the Smiths require genetic counseling. I will first discuss the study of genetics to familiarize the reader with the basic terminology used by physicians and genetic counselors. Next I will discuss the wrongful life and wrongful birth case law. The courts in the United States have had a direct impact on the

development of a genetic counseling standard of care. Judges and juries have considered whether physicians' negligent genetic counseling should be considered the proximate cause of a child's injury. A child's genetic disorder, such as Sara Smith's spina bifida, is caused by a genetic mutation and not by a physician's negligence. However, the courts have established that a physician's failure to counsel a pregnant woman about her fetus with a genetic disorder can be considered the proximate cause of the birth of the child.

I will discuss the treatment of wrongful life and wrongful birth suits by the federal courts. Since suits alleging medical malpractice in military hospitals can only be brought in federal courts, the manner in which the federal judges have treated genetic counseling issues is an important consideration on the impact of wrongful life and wrongful birth suits in military hospitals.

The increased emphasis on genetic counseling has created legal issues in physician-patient interactions involving pre-natal care. I will discuss the development of the genetic standard of care, informed consent and genetic counseling, genetic counseling issues peculiar to military issues, and confidentiality of genetic information. These issues may arise in the context of wrongful life and wrongful birth suits. However, it is possible that they may arise as separate claims by parents and children.

Next I will consider the diagnostic tests available for in-utero diagnosis of genetic disorders. It is important to understand the information which can be provided by diagnostic tests to evaluate a physician's choice of tests with a particular patient. Military physicians must determine if diagnostic tests available in the local civilian medical community are necessary for their patients when the tests are not yet available in the military medical system. An understanding of tests available in both military and civilian hospitals clarifies the choices

military physicians must present to military families during the genetic counseling process.

The improvements in diagnostic testing for genetic disorders have expanded the availability of fetal surgery to correct genetic anomalies. When a surgeon corrects a genetic disorder in-utero, he is operating on a patient within another patient's body. Most pregnant women will not object to an operation when it will benefit their unborn children. As these in-utero surgical procedures become more common, there will be women who object to the surgical procedures because of religious or personal health concerns. I will discuss the legal issues that may arise between mothers and unborn children in the surgical extension of genetic counseling.

This article will not address the related areas of wrongful pregnancy and negligent genetic screening except as they relate to the development of wrongful life and wrongful birth claims. Wrongful pregnancy cases occur when the negligent act of a physician or other health care provider causes an elected birth control measure to fail resulting in the conception of an unwanted child.¹⁴ Genetic screening is the testing of a baby after birth for genetic disease. Genetic screening usually occurs within the first several days of an infant's life.¹⁵

II. GENETICS

Genetics is the study of the inherited variations in human beings. Genes are the basic units of heredity. An individual's genetic composition, commonly called his genome, is established at conception. Each gene contains molecules of deoxyribonucleic acid (hereinafter DNA). DNA is the molecular basis of inheritance in humans as well as most plant and animal organisms. It has the ability to replicate itself so that when a cell divides, each new cell receives a complete, identical copy of the original cell's genetic information. DNA also directs the synthesis of amino acids which

are the basic elements of protein. The discovery of DNA in 1953 has led to rapid advances in the study of genetics.

Each gene contains a small segment of DNA. The genes are carried by chromosomes which are rod-like structures in the nucleus of every cell. Each cell has forty-six chromosomes which are arranged in twenty-three pairs. Each pair contains one chromosome from the mother and one chromosome from the father. Each pair of chromosomes has the same sequence of particular genes known as alleles. Twenty-two of the chromosome pairs are called autosomes while the final pair are called the sex chromosomes. Males have X and Y sex chromosomes while females have two X sex chromosomes.¹⁶

The human body is made up of somatic cells and germ cells. Somatic cells compose major parts of the body such as tissues and organs. Eggs and sperm are called germ cells. During the formation of eggs or sperm, the number of chromosomes is halved by meiosis. During fertilization, the egg's twenty three chromosomes join with the sperm's twenty three chromosomes to form the full set of forty six chromosomes in a new human. The fertilized egg then undergoes mitosis (cell division) which results in identical new cells being formed. The development of a human being occurs from multiplication of cells and their differentiation into various body parts. All cells in a human being contain identical genes. The genetic information is expressed differently in each cell with only a small fraction of the genes remaining active to determine the cell's function.

Genes are arranged in specific patterns in the chromosomes. A mutation is a change in the number, arrangement, or molecular sequence of genes. Mutations may occur on a de novo basis or they may be inherited. Mutations are the basis of evolution and every person inherits mutations that may cause genetic diseases under certain circumstances. Genetic diseases are classified by type. Monogenic diseases involve a mutation in a

single cell. Multifactorial diseases involve an interaction between the environment and more than one gene. A chromosomal disease is caused by a defect in the genetic material (DNA).¹⁷

Genetic counseling is the process of providing prospective parents with risk estimates of the above-described genetic diseases. In order to give genetic advice, a precise diagnosis of the disease in the proband, the person who originally had the disease, must be made. Next, the genetic counselor will attempt to establish an accurate family pedigree so that the mode of inheritance can be determined. Once these steps have occurred, the genetic counselor estimates the risks of the genetic disorder.¹⁸

III. WRONGFUL LIFE AND WRONGFUL BIRTH SUITS

A. WRONGFUL LIFE

A wrongful life claim, which is brought by an infant or on his behalf, alleges that the treating physician negligently advised or counseled the plaintiff's parents concerning genetic risks. The plaintiff in a wrongful life suit alleges that the physician's failure to adequately counsel his parents prevented his parents from making an informed decision on whether to avoid the plaintiff's conception or birth. A wrongful birth claim is usually brought as a companion action with a wrongful life claim. The parents in a wrongful birth claim are seeking damages for the costs of childrearing as a result of negligent genetic counseling.

The expansion in the number of wrongful life and wrongful birth suits is related to the increased use of amniocentesis since the late 1960's. With the improved ability of physicians to diagnose prenatal diseases,¹⁹ patients have expected physicians to use their new diagnostic techniques to provide them with increasingly detailed information about their unborn children. The unprecedented ability to consider a fetus' condition in-utero became

extremely important after the Supreme Court's decision in Roe v. Wade.²⁰ The Supreme Court ruled that women have a constitutional right of privacy under the fifth and fourteenth amendments to make abortion decisions during the first trimester of pregnancy.²¹ After the first trimester, states can regulate abortions as long as the rules are reasonably related to protecting the health of pregnant women.²²

Since the Roe v. Wade decision there has been an increasing number of suits for both wrongful life and wrongful birth. Claims for wrongful life are solely the claims of deformed children against third parties for negligence in failing to prevent conception or failing to give the child's parents the opportunity to obtain an abortion.²³

The wrongful life claim is distinguishable from wrongful pregnancy as well as claims often called impaired life claims. The terms wrongful life, wrongful pregnancy, and impaired life are often used interchangeably by courts and commentators. Wrongful pregnancy claims are usually defined as claims for the birth of a healthy unwanted child as the result of the negligence of a doctor or pharmacist. Examples of wrongful pregnancy claims are physicians who negligently perform tubal ligations and pharmacists who negligently fill birth control prescriptions.²⁴ Dissatisfied life claims are brought by healthy children against either a parent or a third party with the injury usually being described as the stigma of illegitimacy. The first such case was Zepeda v. Zepeda²⁵ where the plaintiff sued his natural father for enticing his mother to engage in sexual intercourse. The plaintiff alleged that he had the right to be born as a legitimate child or not at all. The Illinois Appellate Court affirmed the trial court's dismissal of the suit by relying on public policy grounds.²⁶ The court ruled that to allow a suit based on the plaintiff's illegitimacy would allow future suits for a person's color, for being born into a large family, or for a parent with an unsavory reputation.²⁷ The Zepeda court named the plaintiff's claim a wrongful life suit,²⁸ but the term has subsequently been used to describe a child born with a genetic disorder.

The first use of the term "wrongful life" to describe a genetic disorder was by the New Jersey Supreme Court in Gleitman v. Cosgrove.²⁹ The plaintiff in Gleitman v. Cosgrove was born blind, deaf, and mentally retarded. The plaintiff's mother was exposed to rubella (German measles) during her pregnancy.³⁰ The Gleitmans claimed that if their doctor told them Mrs. Gleitman's rubella could have affected their fetus, Mrs. Gleitman would have elected to have an abortion.³¹ The New Jersey Supreme Court denied recovery on public policy grounds by stating that: 1) it would be impossible to measure damages in wrongful life cases; 2) the court could not sanction abortion as an alternative choice for the parents given the 1967 public policies; and 3) the difficulty of evaluating life with birth defects versus nonexistence.³²

In 1977 the New York Supreme Court, Appellate Division, in Park v. Chessin,³³ considered the case of an infant who died of polycystic kidney disease³⁴ within five hours of birth. Prior to the mother becoming pregnant for a second time, the couple sought genetic counseling. The defendant physicians allegedly advised the parents that there was practically no chance of having a second child with polycystic kidney disease since the disease was not hereditary. When the Parks' second child was born with polycystic kidney disease, the parents filed a suit on behalf of their daughter for wrongful life. The trial ruled in favor of the Parks but the New York Court of Appeals, citing the staggering public policy implications, reversed Park as well as the companion case of Becker v. Schwartz.³⁴

The Gleitman and Park cases are examples of the two types of wrongful life suits. In Gleitman, the plaintiffs sued for the alleged breach of a post conception duty of the treating physicians to advise the plaintiffs of the implications of the mother's exposure to rubella after she was pregnant. In Park, the plaintiffs sought genetic counseling prior to deciding

to have a second child. The duty breached was the obligation to provide accurate information concerning the risks of genetic diseases.

Courts in many states have considered both preconception and postconception wrongful life claims.³⁵ California, Washington, and New Jersey are the only state supreme courts which presently recognize the claims for wrongful life.³⁶ California first considered a wrongful life suit in 1980. The plaintiff in Curlender v. Bio-Science Laboratories³⁷ was born with Tay-Sachs disease after the defendants allegedly performed a screening test for the disease in a negligent manner. An appellate court ruled that the child could recover general damages for pain and suffering, punitive damages, and any special damages not covered by the parents' wrongful birth claim.³⁸

In 1981 a different California appellate court, in Turpin v. Sortini,³⁹ declined to follow the Curlender court and rejected the plaintiff's wrongful life claim for the infant plaintiff who was born with a rare form of hereditary total deafness. Since the two appellate courts differed on wrongful life suits, the California Supreme Court heard the Turpin case on appeal and reversed the lower court.⁴⁰ While recognizing wrongful birth as well as wrongful life, the court refused to allow the infant plaintiff to recover general damages. The court allowed the infant plaintiff to recover only special damages for the "extraordinary expenses necessary to treat the hereditary ailment."⁴¹

As part of the majority opinion, the Turpin court analyzed California Civil Code § 43.6 which bars a child from filing a wrongful life claim against his parents.⁴² The court ruled that the legislature's purpose in enacting the statute was to eliminate any liability or other economic pressure which could cause parents to abort or decline to conceive a defective child.⁴³ The California appellate courts that have considered wrongful life cases have followed the Turpin formula for awarding only special damages.⁴⁴

The Washington Supreme Court was the next court to recognize the right of a genetically injured child to sue for wrongful life. In Harbeson v. Parke-Davis,⁴⁵ the court considered an FTCA action for wrongful life and wrongful birth suit filed by a U.S. Air Force sergeant, wife, and two daughters for alleged negligent genetic counseling. The Harbeson children were born with fetal hydantoin syndrome.⁴⁶

The Harbesons based their suit on medical care Mrs. Harbeson received at Madigan Army Medical Center (MAMC) in Tacoma, Washington. In ruling on the FTCA claims, Judge Tanner stated that the physicians at MAMC had been negligent in failing to inform Mrs. Harbeson of the dangers of becoming pregnant while taking Dilantin, a drug used to control epileptic seizures. The court ruled that Mrs. Harbeson took Dilantin before and throughout the pregnancies of her two daughters and her ingestion of Dilantin was the proximate cause of her daughters' injuries.⁴⁷ Judge Tanner certified questions of law regarding wrongful life and wrongful birth to the Washington Supreme Court.

The Washington Supreme Court held that wrongful life and wrongful birth causes of action could be brought in Washington.⁴⁸ The court, however, limited damages for wrongful life actions to special damages attributable only to the children's genetic defects.⁴⁹ The court rejected the concept of general damages in wrongful life suits due to the impossible task of valuing life with genetic defects versus non-life.⁵⁰

In 1984, the New Jersey Supreme Court in Procanik v. Cillo⁵¹ followed the California and Washington Supreme Courts in allowing a plaintiff born with a genetic disorder to file a wrongful life action. Mrs. Procanik allegedly was exposed to rubella (German measles) during her pregnancy and claimed the defendant doctor told her that she had become immune to German measles during her childhood. Peter Procanik was born

in December, 1977, with congenital rubella syndrome. Peter was blind with a hearing deficit and heart disease.⁵² The court ruled that Peter or his parents could recover medical expenses during his childhood and Peter could recover his extraordinary expenses during his majority. The court rejected Peter's claims for general damages for emotional distress and the loss of enjoyment of his childhood.⁵³

No other state supreme court has followed California, Washington, and New Jersey in recognizing wrongful life suits. The highest courts in Illinois, New Hampshire, and North Carolina have recently rejected wrongful life actions.⁵⁴ The legislatures in South Dakota and Minnesota have prohibited wrongful life actions.⁵⁵

The difficulty in evaluating general damages for the value of life with genetic defects versus non-life has limited the acceptance of the tort of wrongful life. Certainly, the idea of awarding damages to a child for his injury of being born will continue to be controversial. Since the three courts that have allowed the action have limited damages to extraordinary medical expenses, it appears that wrongful life actions will be slow to gain acceptance in American courts notwithstanding the legal commentators who have proposed expansion of the tort of wrongful life.⁵⁶

B. WRONGFUL BIRTH

Wrongful birth actions are usually brought by parents in conjunction with wrongful life suits filed on behalf of their injured children. The parents' suits are intended to compensate them for their injuries separately from the damages claimed by the injured children. Most courts have allowed wrongful birth suits while rejecting wrongful life suits.⁵⁷ Judges have no difficulty analyzing wrongful birth suits in traditional terms of duty, breach of duty, proximate cause, and damages.

Courts have looked to the precedent of wrongful pregnancy cases to begin their analysis of damages in wrongful birth suits. In wrongful pregnancy cases, plaintiffs are normally awarded general damages for the mother's pain and suffering, emotional distress, and loss of consortium. Special damages have included the loss of the mother's wages, medical and hospital expenses.⁵⁸

There is not a consensus for recovery of the costs of childrearing in wrongful pregnancy cases. The majority of courts have not allowed recovery for the costs of raising healthy children. Courts have expressed the view that the expenses of raising children are too speculative and doctors should not have to bear the unreasonable burden of childrearing damages.⁵⁹

The courts that do allow the recovery of childrearing costs often offset them from the anticipated monetary and emotional benefits that the parents will receive from the child.⁶⁰ The benefit offset rule is the public policy doctrine which focuses attention on the value society places on life and family while providing a remedy to parents who have a valid negligence claim.⁶¹ Since every family is different, courts often consider family size and the financial resources available before calculating the offset.⁶²

Courts initially rejected wrongful birth claims using similar rationale as in the companion wrongful life suits. In Gleitman v. Cosgrove,⁶³ the New Jersey Supreme Court ruled that it was impossible to balance the benefits of parenthood versus non-life. The Gleitman court held that the sanctity of human life required parents to hold on to life even if the child had defects.⁶⁴ A year later, in 1968, a New York appellate court denied a wrongful birth claim citing the general public policy ground of opposition to abortion.⁶⁵

During the early 1970s the refinement of amniocentesis and the Roe v. Wade decision led to the gradual acceptance of wrongful birth claims while courts continued to preclude the acceptance of wrongful life claims. The Supreme Court of Texas in Jacobs v. Theimer⁶⁶ allowed the parents to recover pecuniary damages for the birth of a rubella-syndrome child after the doctor failed to diagnose the mother's German measles during her pregnancy.⁶⁷ Courts in Pennsylvania, New York, and Wisconsin followed the precedent of Jacobs v. Theimer and allowed wrongful birth suits but limited damages to the pecuniary damages caused by the genetic defects of the affected children.⁶⁸ The New Jersey Supreme Court permitted damages for mental anguish, but rejected medical expenses for the child's care.⁶⁹ In Schroeder v. Perkel,⁷⁰ the New Jersey Supreme Court allowed the plaintiff's parents to recover damages for medical expenses.

Other courts that have considered wrongful birth cases have also allowed special damages for medical expenses and emotional distress.⁷¹ The Seventh Circuit was the first federal court of appeals to allow a wrongful birth suit. In Robak v. United States,⁷² the Seventh Circuit reversed the district court's decision and allowed the parents to recover all costs of raising the child and not just extraordinary expenses attributable to the child's genetic disorder. The court awarded damages of almost one million dollars.⁷³

In Harbeson v. Parke-Davis⁷⁴ the Washington Supreme Court ruled the parents of two children with genetic disorders could recover pecuniary damages for the extraordinary medical expenses attributable to their daughters' genetic defects as well as general damages for mental anguish and emotional distress. The court held that any emotional benefits from the birth of the children should be deducted from the award.⁷⁵

Wrongful birth causes of action have been accepted by most courts that have considered them in recent years.⁷⁶ Courts have assessed the

damages payable to parents in wrongful birth suits in a variety of ways. Parents' damages have been limited to special damages for extraordinary medical expenses directly related to the child's affliction in some jurisdictions,⁷⁷ while other jurisdictions have allowed parents to recover general damages for their emotional anguish as well as special damages for extraordinary expenses.⁷⁸ In addition, some courts have allowed parents to recover damages for all costs of raising children if they had not been born with a genetic disorder and not just the extraordinary costs attributable to children's medical expenses.⁷⁹ This minority view to award the costs of raising a healthy child will probably not gain wide acceptance since it is contrary to the public policy of promoting procreation. Courts considering wrongful birth suits have looked to the precedent of wrongful pregnancy suits.⁸⁰ Most jurisdictions continue, on public policy grounds, to deny parents special damages for the costs of raising a healthy child. It is likely that the costs of raising a healthy child in wrongful birth suits will not be awarded in more than a handful of states.

Most of the courts in the United States that have allowed wrongful birth suits have not allowed the child to prevail in a wrongful life action. The judges' opinions rejecting wrongful life suits emphasize the difficulty in measuring general damages in such suits based on the comparison between life with genetic defects and non-life.⁸¹ In the jurisdictions that have allowed wrongful life suits, damages have been limited to the child's special damages for the extraordinary expenses attributable to the genetic disorder.⁸²

It is likely that there will be a gradual acceptance of wrongful life suits in the United States based on two distinct theories. First, it is logical that the costs of a child's medical care throughout that person's life should be awarded to the child. When a guardian is appointed for the child and the damages are awarded in the child's name, there is no question that the award will be used for the child's care.⁸³ There is at least one incident of

parents being awarded damages for the expected extraordinary medical expenses of their child born with genetic defects when they had previously given up their child for adoption.⁸⁴ If courts award damages directly to the injured child, there is less likelihood that the award will not be available for the support of a genetically impaired child throughout his life.

The second reason that wrongful life suits are likely to be accepted by more courts is that judges will be forced to consider the public policy basis of the historical rejection of wrongful life suits. While most courts have ruled that it is impossible to decide if life with defects is preferable to non-life there is a growing trend in the United States to allow patients to choose death over life when they are terminally ill. Thirty-five states and the District of Columbia have passed statutes that recognize the right of a terminally ill person to refuse life sustaining treatment or to have life-sustaining treatment withdrawn.⁸⁵ The Army, Air Force, and Navy have established procedures to allow physicians to write do not resuscitate (hereinafter DNR) orders, or no code orders, for patients who have decided that they do not want life saving measures performed if they suffer a cardiac arrest while hospitalized.⁸⁶ Following the successful suit of a seventy-one year old patient to force physicians at Walter Reed Army Medical Center to withdraw life-support equipment⁸⁷ the Army has allowed physicians to order withdrawal of life support equipment if a terminally ill patient makes such a request.⁸⁸

There is certainly a great difference between a terminally ill patient choosing immediate death over a prolonged period of suffering in a hospital while kept alive on a ventilator versus parents choosing non-life versus life with a genetic defect for an unborn child. The trend in our courts, however, is clearly to recognize that death, or non-life in specific instances, may be preferable to life. Given this trend, it seems logical that there will be a gradual acceptance of wrongful life as a valid cause of action in American courts.

A related area to an individual choosing to terminate medical treatment at the end of his life is the substituted judgment of parents to terminate care for an infant born with a severe genetic disorder. The termination of medical treatment for infants born with severe genetic disorders is important to consider since it is an indication of courts' interpretation of the value of impaired life versus non-life. If judges recognize the right of parents to allow severely handicapped children to die shortly after birth, courts will be accepting the argument that non-life may in some instances be preferable to impaired life. Courts should then have less difficulty accepting claims for wrongful life since a plaintiff in a wrongful life suit is arguing his impaired life is worse than non-life if his parents had elected to avoid his birth.

The first Baby Doe suit in Bloomington, Indiana involved an infant born with Down's Syndrome and esophageal atresia, a surgically correctable condition in which food cannot enter the stomach. When Baby Doe's parents would not consent to intravenous feeding and surgery to correct the esophageal atresia, the Bloomington Hospital petitioned the Superior Court of Monroe County, Indiana to determine if the parents' decision was legally binding.⁸⁹ The controversy caused by Baby Doe led the Department of Health and Human Services [hereinafter DHHS] to issue a "Notice to Health Care Providers" that section 504 of the Rehabilitation Act of 1973 [hereinafter Section 504] required hospitals to provide life sustaining treatment to infants or risk losing their federal funding based on section 504's prohibition against discrimination for handicapped individuals.⁹⁰

The DHHS notice to health care providers was followed by issuance of an interim final rule in March 1983 that required federally assisted hospitals to post notices in their delivery rooms, nurseries, neonatal intensive care units, pediatric wards, maternity wards, and pediatric wards that failure to provide food and medical care violated federal law.

Violations of the rules could be reported to DHHS or state child protective services.⁹¹

DHHS modified the rules after strong opposition from most medical groups concerning the reporting requirements. The final rules, issued in 1984, were also based on section 504 of the Rehabilitation Act of 1973. The rules state that medically beneficial treatment should not be withheld from a handicapped infant solely on the basis of handicap.⁹²

The Supreme Court, in a plurality opinion written by Justice Stevens, ruled that DHHS could not use section 504 of the Rehabilitation Act of 1973 as a basis for enforcement of the mandatory provisions of the Baby Doe regulations requiring posting of the regulations, mandatory reporting to state agencies, access to medical records, and expedited action to effect compliance.⁹³ Justice Stevens concentrated on the necessity for DHHS to promulgate a regulation where there was a "rational connection between the facts found and the choices made"⁹⁴ by the agency. Justice Stevens found no rational connection between the DHHS regulations and the fact that HHS could document no cases where a hospital had refused to furnish medical care to a handicapped infant or had refused to report cases of medical neglect of newborns by parents to a state child protective service.⁹⁵ The effect of the Supreme Court decision is to reaffirm the authority of state agencies to review decision of parents to withhold medical treatment from infants.

Since state agencies are generally more aware of the particular family dynamics involved in specific cases, there has been little public controversy regarding withholding of medical treatment of severely handicapped children since the Bowen decision. This does not mean that no such decisions are being made in American hospitals. Withholding of medical treatment from infants has quietly become more common. Military hospitals are no exception to this trend. Ethics committees in

military hospitals composed of physicians, lawyers, chaplains, nurses, and social workers have aided families in the difficult decision of withholding care from severely injured infants. Parents in these situations have made the decision that death for an infant is preferable to a life of unending suffering for their child.

Courts will inevitably follow the precedents established by the patients who request no code orders and the parents who decide to allow their children to die in the manner of the Baby Doe case. The public policy arguments precluding wrongful life suits will slowly change to allow parents to choose to have an abortion. Certainly, many parents faced with the knowledge that their unborn child has a genetic disorder will elect to have the child. However, the issue in wrongful life suits, is whether the child can maintain an action for the failure to allow the parents a choice to abort the child.

C. THE FEDERAL COURTS AND WRONGFUL LIFE AND WRONGFUL BIRTH SUITS

A federal court must apply the state law as it existed at the time and place of the tort which is the subject of a Federal Tort Claims action.⁹⁶ Federal judges have gone to extraordinary lengths to allow sympathetic plaintiffs to maintain actions under the Federal Tort Claims Act for the birth of a genetically impaired child. One of the first federal courts to consider a wrongful life/wrongful birth suit was the District Court in the Eastern District of Pennsylvania. The court in Gildiner v. Thomas Jefferson University Hospital ruled that the plaintiffs could maintain an action for wrongful birth under Pennsylvania law for a negligent amniocentesis which allegedly prevented the parents from electing to abort a child born with Tay-Sachs disease.⁹⁷ The court did not cite any Pennsylvania authority for the proposition that a wrongful birth action was actionable, but stated that the public policy of Pennsylvania supported

recognition of a wrongful birth cause of action under general negligence theory.⁹⁸

In December 1980, the United States District Court for South Carolina ruled, in Phillips v. United States,⁹⁹ that a wrongful life action was not recognized under South Carolina law for an infant born with Down's Syndrome at Charleston Naval Hospital.¹⁰⁰ The court predicted that if the South Carolina Supreme Court considered a wrongful life suit it would deny such a cause of action on public policy grounds. One month later, the same court held the plaintiffs could maintain an action for wrongful birth despite the fact that the South Carolina Supreme Court had not ruled on such a claim.¹⁰¹ The court ruled that since the South Carolina Supreme Court had favorably considered a wrongful pregnancy action and there were six other jurisdictions in the United States where wrongful birth suits had been recognized, it was likely that the South Carolina Supreme Court would favorably consider a wrongful birth cause of action and the District Court denied the United States' summary judgment motion.¹⁰²

At trial, the South Carolina District Court ruled that the Navy physicians had been negligent in failing to provide the Phillips family with adequate genetic counseling.¹⁰³ The court later awarded \$1,533,865.00 to the plaintiffs. The economic loss included damages for emotional distress and economic loss which included only the extraordinary expenses of childrearing attributable to the child's genetic disorder.¹⁰⁴

In Robak v. United States,¹⁰⁵ the Seventh Circuit affirmed the district court's ruling that a wrongful birth action was cognizable under Alabama law while holding that all childrearing costs were recoverable in a case where the child was born with rubella syndrome in 1972. The Seventh Circuit had no difficulty holding that the Alabama Supreme Court would allow such an action under traditional tort law principles despite the Alabama Supreme Court's unanimous refusal to consider the district court's

certification of questions of law regarding wrongful life and wrongful birth.¹⁰⁶ The Robak decision was significant since it continued the precedent of the Phillips court to predict how a state court would rule in the absence of a state supreme court decision. The Robak court was predicting that the Alabama Supreme Court would have allowed such an action in 1972 when the Robak child was born at a time when wrongful birth was recognized in only a few jurisdictions. Since abortion was illegal in Alabama in 1972, even if the Robaks had been told of the likelihood of rubella syndrome, they could not have aborted their child. The Seventh Circuit's willingness to predict the state court's ruling provided the precedent for other federal courts to be judicially active when considering wrongful life and wrongful birth suits.

The Ninth Circuit considered a case similar to Robak in Harbeson v. Parke-Davis,¹⁰⁷ but its decision was made easier by the Washington Supreme Court which responded to questions of law certified by the federal district court for the Western District of Washington and held that wrongful life and wrongful birth actions were recognized under Washington law.¹⁰⁸ The Ninth Circuit affirmed the district court's verdict for the plaintiff's for the birth of two children with fetal hydantoin syndrome and ruled that the treating physicians at Madigan Army Medical Center should have disclosed the material risks of the drug Dilantin to the mother during her pregnancy.¹⁰⁹

The United States District Court for the Middle District of North Carolina considered a pre-conception genetic counseling case in Gallagher v. Duke University.¹¹⁰ While denying a wrongful life cause of action, the court ruled that the suit for wrongful birth for pre-conception genetic counseling was distinguishable from the court's decision in Azzolino v. Dinghelder¹¹¹ where the North Carolina Supreme Court refused to recognize wrongful life and wrongful birth suits in a post-conception genetic counseling case. In Azzolino, the court ruled that absent

legislative action, it would not allow wrongful life and wrongful birth suits.¹¹² Given the North Carolina Supreme Court's ruling, the federal district court's decision to allow a pre-conception wrongful birth suit is stretching the bounds of credibility. The Gallagher decision clearly shows that federal courts will have no hesitancy to allow wrongful birth suits if there are no state supreme court decisions which have similar fact patterns.

A related development to the acceptance of wrongful life and wrongful birth suits is the consideration of such suits by active duty servicemembers and their children. Such suits under the Federal Tort Claims Act are generally barred by servicemembers who are injured incident to their military service by the Supreme Court's ruling in Feres v. United States.¹¹³ Courts analyze servicemember's location, duty status, and activity at the time of the injury to determine if the Feres bar is applicable.¹¹⁴ Claims which are derivative from the claims filed by active duty servicemen are barred, even if there is an independent cause of action under state law.¹¹⁵ The Fifth Circuit¹¹⁶ and the Ninth Circuit¹¹⁷ have refused to allow a child to maintain an action for negligent genetic counseling provided to their respective active duty parents.

In a similar case, the Seventh Circuit in West v. United States¹¹⁸ initially ruled that Feres did not bar a claim for injuries suffered by two children of a former soldier whose blood was mistyped at his induction. The blood mistyping allegedly caused the West's daughters to be born with birth defects. The Seventh Circuit held that the claim of the daughters was not barred by Feres. The court ruled the daughters' action did not effect military discipline, that there was no distinctively federal relationship related to the daughters' medical care, and no alternative federal compensation scheme. The court held there was subject matter jurisdiction and remanded the suit to the district court.¹¹⁹ On rehearing en banc, the Seventh Circuit reversed its earlier decision and upheld the

district court's dismissal for lack of subject matter jurisdiction under Feres.¹²⁰

In a case which relied on the original 7th Circuit decision in West, the United States District Court for the Southern District of Indiana in Utley v. United States¹²¹ held that a child could maintain an action for negligent prenatal care provided to the plaintiff's mother while the mother and father were on active duty in the Air Force. The court held there was no injury to the parents and since the only injured party was the child, the suit had a minimal effect on military discipline. Since there was no distinctly federal relationship and the plaintiff child had no redress with the federal compensation system, the court had subject matter jurisdiction.¹²² After the Seventh Circuit's decision in West was overturned on rehearing, the Utley court's reliance on West was unfounded and Utley has no precedential value.

In another wrongful birth suit, the United States District Court for the Eastern District of California dismissed a plaintiff's suit for negligence in treating her active duty mother with the drug benedectin to control the mother's nausea.¹²³ The court held that it had no choice but to dismiss the child's action based on Feres despite its sympathy for the child's plight.¹²⁴

All of the cases which discuss wrongful life and wrongful birth claims of active duty servicemembers and their children have barred the actions based on Feres.¹²⁵ The lone exception is the federal district court in the Southern District of Indiana which relied on a Seventh Circuit Court of Appeals decision which was subsequently reversed. The United States has fared well in defending wrongful life and wrongful birth suits when the mother of the child was on active duty during the mother's prenatal treatment.

The United States' success in defending wrongful life/wrongful birth suits brought by active duty mothers and their children faces a significant challenge in the Ninth Circuit's recent decision in Atkinson v. United States.¹²⁶ The Ninth Circuit held that an active duty mother allegedly mistreated for preeclampsia at Tripler Army Medical Center could maintain an action for medical malpractice notwithstanding Feres.¹²⁷ The court held that the Supreme Court's decision in United States v. Shearer,¹²⁸ mandated an independent review of each suit to determine the effect of the suit on military discipline and decisionmaking.¹²⁹ The court held that no military discipline applies in the treatment of a pregnant soldier in a non-field hospital who was seeking treatment for complications of pregnancy.¹³⁰ The Ninth Circuit did not consider the military interest in maintaining a healthy military force and the fact that the plaintiff was on a military installation in a duty status during her medical treatment. Based on these factors, the United States will have a strong argument for reversal on rehearing or appeal.

IV. GENETIC COUNSELING AND THE LAW

A. STANDARD OF CARE

To avoid liability for wrongful birth or, where permitted, wrongful life, the genetic counselor must conform to the medical standard of care. The standard of care in medical malpractice cases has generally been the medical custom of a particular specialty. The practice of using medical custom as the standard of care developed at least, in part, because judges and juries are usually incapable of deciding, due to the complexities of medical treatment, if a doctor has acted in a negligent manner in the treatment of a patient.¹³¹

The courts that have accepted the wrongful birth cause of action have had no difficulty establishing that genetic counselors owe a duty of

reasonable care to prospective parents.¹³² Similarly, the courts that have recognized the wrongful life cause of action have held that the genetic counselor has a duty to the young child even though the negligence may occur prior to conception.¹³³

One difficulty with establishing the standard of care for genetic counselors is the variety of individuals who conduct genetic counseling. Presently, physicians, social workers, nurses, and geneticists, usually Ph.D.s, may all conduct genetic counseling. The American Board of Medical Genetics began certifying geneticists in 1981. There are different tests for physicians and genetic counselors who have Ph.D.'s, master's degrees or are registered nurses.¹³⁴ Since most genetic counseling centers are hospital based, courts will probably establish a single standard of care for genetic counseling, based on a physician and hospital standard of care. The wrongful birth and wrongful life cases have clearly established the duty of physicians to advise patients of the risks of a child being born with a genetic defect. With the increasing number of genetic counseling centers in the United States, treating physicians will not only have the duty to initially counsel prospective parents at risk, but to refer couples to genetic counseling centers if appropriate. The physician who first examines a pregnant woman or conducts pre-conception counseling has the responsibility to determine if genetic counseling is necessary. The generally accepted standards for referral to a genetic counselor are:

- genetic or congenital anomaly in a family member;
- family history of an inherited disorder;
- abnormal somatic or behavioral development in a child;
- mental retardation of unknown etiology in a child;
- pregnancy in a woman older than age 35;
- specific ethnic background suggestive of a high rate of genetic abnormality;

- drug use or long-term exposure to possible teratogens or mutagens;
- three or more spontaneous abortions, early infant deaths, or both; and
- infertility.¹³⁵

The initial treating physician has the responsibility to take a family history with family pedigree. The patient's family history should be confirmed by family medical records whenever possible if indicated by the previous occurrence of genetic disorders. When the family history information reveals the possibility of genetic disorders, chromosome analyses or carrier diagnostic tests are indicated.¹³⁶

Since chromosome analysis and carrier screening are not routinely performed by treating physicians, couples requiring pre-conception counseling are often referred to genetic counselors. If a child has already been conceived, the physician may continue treating the family if appropriate. For example, it is the standard of care for physicians to conduct amniocentesis for all women thirty-five or older to detect the possibility that the fetus may have Down's Syndrome.¹³⁷ Once the treating physician receives the results of amniocentesis, he may then choose to refer the family to a genetic counselor.

After a physician refers parents to a genetic counselor, a four-step process is followed. First, the genetic counselor will continue to gather information about the family history by testing family members and reviewing medical records. Second, the genetic counselor will relay the information to the family including the degree of risk of occurrence of a genetic disorder that occurred in a previous child or the degree of risk based on diagnostic tests. Next, the counselees are given time to evaluate the risks of attempting to become pregnant or continuing a pregnancy. Finally, the genetic counselor must assist the parents in deciding whether

to conceive as prospective parents or to continue a pregnancy following conception.¹³⁸

The most critical element in the genetic counseling process is the ability of the prospective parents to understand the risks of genetic disorders. Studies of individuals who have undergone genetic counseling indicate that counselees have varying degrees of difficulty in understanding the risks of genetic disorders in their unborn children.¹³⁹

Historically, physicians have debated whether they should perform directive or non-directive genetic counseling.¹⁴⁰ Counselors who advocate directive genetic counseling favor the view that parents have difficulty understanding the risks of genetic disorders and genetic counselors should direct the family to choose the alternative the counselor considers the appropriate decision. However, the more prevalent method of counseling is the non-directive approach where the counselor presents the alternatives to the parents and the parents make their own decision.¹⁴¹ The non-directive approach to genetic counseling should remain dominant since the trend in medicine is for patients to have greater autonomy in health care decisions.

B. GENETIC COUNSELING ISSUES IN MILITARY HOSPITALS

Physicians who counsel parents desiring pre-conception or post-conception genetic counseling must carefully consider whether they are qualified to offer genetic counseling. Genetic counseling is very different from the normal physician-patient relationship, which involves the diagnosis and treatment of an injury or disease in a single patient. In a genetic counseling situation, the physician is discussing the risks of a child being born with a genetic disease. Certainly, obstetricians and family practitioners are capable of beginning the genetic counseling process with families. Depending on the facts of each family history, the treating physician may desire to refer the family to a genetic counselor who can devote more time to studying the family history.

It is foreseeable that a physician's failure to adequately perform genetic counseling could result in the birth of an impaired child. The physician's failure to adequately perform genetic counseling does not cause, in a factual sense, a child to be born with a genetic defect. The child's genetic disorder is inherited and not caused by the physician. The physician's failure to adequately counsel the parents, however, has been held to deny the parents the opportunity to elect to have an abortion. In other words, while not the factual cause of the child's defects, the physician's negligence is the legal or proximate cause.¹⁴²

A physician's decision to conduct genetic counseling rather than referring a family to a genetic counselor will come under close scrutiny in a wrongful life/wrongful birth cause of action. The counseling physician's decision not to refer to a genetic specialist will usually be considered in terms of customary medical practice in similar cases.¹⁴³ Courts have ruled that primary care physicians need not become experts in genetic counseling.¹⁴⁴ Courts have also held, however, that physicians have the duty to refer families to genetic counselors in appropriate situations.¹⁴⁵

Military family practitioners and obstetricians usually work in high volume practices. It is difficult, therefore, for most military physicians to perform the time-consuming process of genetic counseling. Small military hospitals often have limited numbers of obstetricians on their staffs and they are extremely busy. Thus, at small military hospitals, military physicians may have to refer families to civilian genetic counselors. Military medical centers often have perinatologists (obstetricians who specialize in maternal-fetal medicine) who can perform genetic counseling.

An important consideration in a genetic counseling situation with a military patient is who will pay for counseling at a civilian counseling center. Active duty servicemembers and their family can be reimbursed

for the costs of genetic counseling through the CHAMPUS health care program.¹⁴⁶ Military families are likely to be more receptive to civilian genetic counseling if they know they will not be required to pay for the entire costs of counseling.

C. INFORMED CONSENT AND GENETIC COUNSELING

As genetic counseling practices have become more refined with the development of amniocentesis since the late 1960's, physicians have also had to consider the development of informed consent requirements. The term informed consent was first used in 1957 by a California appellate court to describe the requirement of a physician to disclose the risks of a medical procedure and to obtain the patient's permission to perform a medical procedure.¹⁴⁷ A landmark opinion of the Kansas Supreme Court in 1960 further developed the informed consent doctrine.¹⁴⁸ Since 1960, a majority of states have adopted the informed consent requirement.¹⁴⁹

Two different informed consent standards have developed since 1960. The first standard, adopted by a majority of states, is based on the professional custom of physicians.¹⁵⁰ This requires a plaintiff to produce expert witnesses who describe the information normally disclosed by the medical community about a particular ailment. The second standard, the patient based standard, requires that physicians disclose all information that a reasonable patient would consider material before consenting to a medical procedure.¹⁵¹

Patients have the authority to make decisions about their health care under either informed consent standard. In the initial phases of a genetic counseling situation, the counselor or physician has the obligation to disclose the nature of diagnostic tests, the risks and benefits of each test, and fully disclose the results of the tests if the patient elects to undergo the tests. A physician must decide which patients require information about the possibility of referral to a genetic counselor.

The President's Commission considered this problem in the context of amniocentesis. The medical standard of care mandates amniocentesis for women age 35 and older.¹⁵² However, a 34 year old woman has a one in four hundred and sixty-five chance of giving birth to a child with Down's Syndrome, while a thirty-five year old has a one in three hundred and sixty-five chance.¹⁵³ The President's Commission argues that it is not logical to counsel thirty-five year olds on the risks of Down's Syndrome while not counseling thirty-four year olds.¹⁵⁴

Physicians face difficult decisions on when genetic counseling should be offered to families. As a minimum, physicians should offer genetic counseling to those families who meet the criteria established by the American Medical Association.¹⁵⁵ A physician practicing defensively could theoretically offer diagnostic testing to every pregnant woman. While this would be impracticable and expensive, the modern trend is towards more patient autonomy and an increased emphasis on non-directive genetic counseling which will lead to diagnostic genetic testing being offered to more families.

Certainly, the United States would have been in a better position to defend the suit filed by Sergeant and Mrs. Smith in the opening hypothetical if the treating physicians at Ford Army Hospital had discussed the necessity of genetic counseling with the Smiths. Military physicians in their high volume practices have to guard against making unilateral health care decisions without advising patients of the genetic counseling options. It is certainly simpler for physicians to arbitrarily decide which patients require genetic counseling. Courts have repeatedly demonstrated, however, that patients make their own health care decisions after considering their physician's advice. Military physicians would be well-advised to inform patients who have the risk factors identified by the American Medical Association of the availability of genetic counseling and diagnostic testing.

D. CONFIDENTIALITY OF GENETIC INFORMATION

Once a pregnant woman has undergone diagnostic testing, the physician or genetic counselor faces another dilemma. The counselor must decide if he should release all test results or only the results of the single test which caused the family to request genetic counseling.

An example of this situation is a family that has four daughters. If one daughter has Down's Syndrome and the mother is pregnant with her sixth child, she will probably choose to undergo amniocentesis. If the test proves negative for Down's Syndrome, but reveals that the fetus is female, does the genetic counselor have the obligation to reveal that fact to the family? The counselor may hesitate to reveal the sex of the child if he fears the family will choose to abort what appears to be a healthy fetus if the parents do not want another daughter. The physician has the obligation, under the informed consent doctrine, to reveal all results of diagnostic tests. However, the physician can refuse to participate in the abortion if he objects on moral grounds.¹⁵⁶ If a family proceeds to a full genetic work-up, the genetic counselor has the obligation to provide the family with all pertinent information about the genetic disorder and the risks of the unborn child inheriting the disorder.

Physicians face a more difficult question when considering the release of genetic information to third parties other than the parents who are undergoing genetic counseling. Physicians normally keep all patient medical information confidential. Therefore, physicians normally do not reveal genetic counseling information to anyone other than the prospective parents. There has been judicial acceptance in the United States of the confidential relationship between physicians and patients. The privilege is based on society's desire to encourage free and open discussions between doctors and patients. Licensing statutes in many states prohibit physicians

from disclosing confidential patient information for the benefit of society as well as the particular patient.¹⁵⁷

A second basis for confidentiality of the physician-patient relationship is the testimonial privilege statutes. These statutes prevent physicians from testifying in court without the patient's consent.¹⁵⁸ The testimonial privilege between physicians and patients is not applicable to active duty servicemembers.¹⁵⁹ The testimonial privilege does not protect dependents and retired servicemembers who are litigants in federal courts under the federal common law. Federal courts have generally not recognized the physician-patient privilege.¹⁶⁰

The statutory exceptions to confidentiality of patient information relate to public health issues. Physicians in most states have the duty to report individuals with contagious diseases to public health agencies.¹⁶¹ Officials in public health agencies will then locate individuals who may have had contact with the infected person. The purpose of these statutes is to locate and treat infected people to limit the spread of contagious diseases.

The other major area where physicians may have a duty to disclose privileged information is to protect the public or to protect specific third parties from their patients. In a widely quoted decision, the California Supreme Court in Tarasoff v. Regents of the University of California¹⁶² ruled that once a physician has a reasonable belief that a patient may injure a specific person, the physician must warn that person.¹⁶³ The Tarasoff decision has been followed by other courts which have considered the psychotherapist's duty to third parties.¹⁶⁴ Some courts have extended the liability of psychotherapists from the readily identifiable victim standard of Tarasoff to a standard of foreseeability of harm to the public in general.¹⁶⁵

The Tarasoff cases are not directly analogous to the genetic counseling situation since the counselee does not present the threat of physical danger to a third party. However, the genetic counselor's situation is similar to the psychotherapist's problem because the genetic counselor may learn of the existence of other people who may be harmed by being carriers of genetic disorders and could become parents of an impaired child. There are no reported cases where a genetic counselor has chosen to communicate the results of diagnostic testing to other affected individuals. The National Society of Genetic Counselors has not established guidelines regarding the confidentiality of genetic information.¹⁶⁶

A physician faced with this dilemma can look to Tarasoff and the many related cases for guidance. Before deciding to release the genetic information to third parties, the physician should carefully analyze the foreseeability of harm to the third parties. If the third parties are of child bearing age and there is a high likelihood they could be carriers of the subject genetic disorder, the physician should release the diagnostic data to the third parties. In such a situation, it is likely a court would hold the physician has a duty to disclose the information to an affected third party.

The physician's duty to third parties in a genetic counseling situation is supported by the courts that have considered a physician's duty to warn third parties of the communicable diseases of his patients.¹⁶⁷ In Gammill v. United States¹⁶⁸ the Tenth Circuit affirmed a district court ruling that the plaintiffs could not maintain an action under the Federal Tort Claims Act for the failure of a civilian physician employed at the U.S. Army hospital at Fort Carson to report his treatment of a patient with infectious hepatitis to the public health authorities in Colorado.¹⁶⁹ The plaintiffs alleged that they would have been contacted by Colorado public health officials if the Army physician had complied with the notice requirements. The court held that since the Army physician did not know the plaintiffs had been exposed to the disease, he had no duty to warn the

plaintiffs.¹⁷⁰ The court ruled that a physician must be aware of the specific risks to specific persons before the physician has a duty to warn.¹⁷¹

In many genetic counseling situations, the treating physician will be aware of specific third parties who may be at risk through his analysis of the family pedigree. While genetic diseases are not contagious, the risk of harm is sufficient to justify a treating physician's decision to warn foreseeable third parties of the risk of transmitting genetic disorders.

Physicians who do release genetic information to third parties will be concerned with the possibility they have breached their duties to their patients by divulging their patients' confidential genetic information. Although federal courts do not generally recognize a physician-patient privilege,¹⁷² military physicians should carefully weigh the consequences of releasing genetic counseling information.

Military physicians or civil service physicians who conduct genetic counseling with active duty military personnel cannot keep the information confidential. The military requires healthy soldiers and medical information that relates to a soldier who may develop a genetic disease must be revealed. Military physicians who routinely treat large numbers of retired soldiers and family members will face issues of confidentiality of genetic information. Individuals entitled to military health care may have strong interests in preventing their employers from learning facts about their genetic composition. Civilian companies may not choose to retain an employee who has a genetic disorder which may become debilitating and cause the employee to miss work. For example, a patient who may develop muscular dystrophy in the future may be dismissed by a company when the employee may miss extended work periods due to illness. Many retired soldiers and family members work for civilian companies. Military physicians should always obtain their patient's consent before releasing

genetic information to employers. A small number of companies now require genetic screening of employees.¹⁷³ As medical technology improves, it is likely that military physicians will face increasing numbers of disclosure issues in employment physicals.

The issue of patient confidentiality in genetic counseling is more likely to occur in the context of a family trying to evaluate the risks of a genetic disorder in a child. When a physician or genetic counselor becomes aware of an inherited family disorder, he must decide whether to inform other extended family members if it is possible they are afflicted with the same disease. Most individuals who are given information about genetic disorders will consent to release of the information to relatives who may be similarly afflicted. If the counselor cannot convince the family to consent to disclose to a family member, the counselor must balance the family's privacy rights versus the need for other family members to receive the information to make informed decisions about their own procreative choices.

A physician in this situation will have to consider the precedent of the public health statutes and Tarasoff. Neither situation is analogous to genetic counseling since genetic disorders are inherited but not contagious and the physician is not considering the need to warn a third party of an imminent violent act. However, the potential harm to a couple considering the conception of a child certainly warrants the counselor warning other family members who may be carriers of a genetic disorder.

An example of the need to disclose genetic information is a woman with a daughter diagnosed with cystic fibrosis refusing to tell her pregnant sister of her daughter's illness. Since cystic fibrosis can be diagnosed in-utero¹⁷⁴ the physician should disclose the risks of cystic fibrosis to his patient's sister who may also be a carrier of the disease if he cannot convince his patient to discuss her daughter's cystic fibrosis with her sister.

V. IN-UTERO DIAGNOSIS OF GENETIC DISORDERS

A. DIAGNOSTIC PROCEDURES

The following brief summary of invasive and non-invasive diagnostic procedures is intended as a starting point for research into a specific procedure. Very few military hospitals have the trained technicians or equipment to conduct all diagnostic procedures. However, military physicians may refer patients to civilian physicians for the tests.

The most commonly used non-invasive procedure by physicians in treating obstetric patients is ultrasonography, commonly called ultrasound. Ultrasound involves the generation of intermittent high frequency sound waves by applying an alternating current to a transducer which is connected to the abdominal wall of a woman by using a coupling agent, usually mineral oil.¹⁷⁵ Since only a small segment of a fetus, called a slice of the fetus, can be viewed in each image, it is feasible only to study limited parts of a fetus' body.¹⁷⁶ Physicians use ultrasound to observe fetal growth and development in-utero. Ultrasound can be used to monitor fetal growth by observing head, trunk, and bone size. Physicians use changes in the ratios of head-abdomen circumference ratio to evaluate growth.¹⁷⁷ Ultrasound can be used to diagnose a variety of fetal conditions.¹⁷⁸

There are no known risks for ultrasound for the mother or child. However, as with all diagnostic procedures, the possibility of undiscovered side effects mandates using ultrasound cautiously.¹⁷⁹

The increase in use of ultrasound has caused a decrease in the use of the other non-invasive procedure for pre-natal diagnosis, roentgenogram (x-ray). Fetal x-rays are used to identify ossified parts of the fetal skeleton

and identify abnormalities such as anencephaly and hydrocephaly.¹⁸⁰ The primary risk of x-ray is exposure to ionizing radiation which can cause injury to cell life.

There are two other radiographic studies, fetography and amniography which involve the introduction of contrast material into the amniotic cavity by needle. The oil soluble contrast material used in fetography adheres to the fetal vernix and allows visualization of the fetal contours. In amniography, a water soluble contrast material is used. The amniotic fluid is opacified by the contrast material.¹⁸¹ Physicians use amniography to diagnose unusually large amounts of amniotic fluid, the abnormally placed placenta, and the fetal gastrointestinal tract after the fetus has swallowed the water soluble material for several hours.¹⁸²

The fetus is at risk for exposure to ionizing radiation in both amniography and fetography just as in normal x-rays.¹⁸³ These invasive procedures are not used as frequently as in the past with the advent of ultrasonography and its apparent lack of risk to the mother and fetus.

Fetoscopy is a relatively new procedure which permits direct visualization of the fetus. Fetoscopy is usually performed between the fourteenth and twentieth week of a pregnancy. The fetoscope is inserted into the amniotic cavity through a small incision in the abdominal wall. Fetoscopy is attempted only after ultrasound scanning to identify the position of the fetus and the placenta.¹⁸⁴ The fetoscope consists of a fiberoptic light source and self-focusing lens. A separate channel on the fetoscope can be used to obtain samples of fetal blood, skin, and liver biopsies.

Analysis of fetal blood samples can be used to diagnose alpha-1-antitrysin deficiency,¹⁸⁵ chronic granulomatous disease,¹⁸⁶ hemoglobinopathies,¹⁸⁷ hemophilia,¹⁸⁸ and homozygous Von Willebrand's

disease.¹⁸⁹ Fetal skin biopsies can be used to diagnose several types of genetic skin diseases.¹⁹⁰ Fetal liver biopsy can be used to diagnose fetal metabolic disorders.¹⁹¹

The primary risks of fetoscopy include spontaneous abortion and premature delivery. The fetal mortality rate is less than five percent.¹⁹² Fetoscopy is only available at several medical centers in the United States.¹⁹³

Amniocentesis is the most widely used invasive diagnostic procedure in pre-natal diagnosis.¹⁹⁴ The amniotic fluid is aspirated between sixteen and eighteen weeks of gestation.¹⁹⁵ Once the amniotic fluid is obtained, it takes three to four weeks in culture to obtain the results. Therefore, the physician can give the family the results at nineteen or twenty weeks gestation.

The primary reason most women undergo amniocentesis is advanced maternal age.¹⁹⁶ Most physicians advise women aged thirty-five and older of the benefits and risks of amniocentesis. This use of an arbitrary age for advising women of amniocentesis has been criticized as arbitrary and illogical.¹⁹⁷ Prudent physicians should carefully consider whether women below the age of thirty-five should be advised of the availability of amniocentesis.¹⁹⁸ Amniocentesis can be used to detect autosomal, metabolic disorders, and X chromosome-linked disorders.

The measurement of alpha-fetoprotein in amniotic fluid between sixteen and twenty weeks of gestation can be used to diagnose many fetal conditions.¹⁹⁹ Normally alpha-fetoprotein levels decrease rapidly after thirteen weeks gestation. Analysis of amniotic fluid could conceivably result in diagnosis of a large number of fetal disorders. However, it would subject most women to unnecessary risks as well as being cost prohibitive to use amniocentesis on large numbers of pregnant women to measure alpha-fetoprotein levels.

Spontaneous abortion is the major risk of amniocentesis. The risk is less than .5% which is low in comparison to the baseline miscarriage rate in the second trimester of 3.5%.²⁰⁰ Amnionitis, amniotic-fluid leakage, and vaginal bleeding occur in less than 1.1% of all cases.²⁰¹

A diagnostic test that is related to amniocentesis is alpha-fetoprotein testing of the blood samples of the mother. AFP testing of the mother's blood between sixteen and eighteen weeks is much safer than performing amniocentesis to measure AFP levels. A high value of AFP in the mother indicates a high risk of neural tube defects. Following a high AFP value in a mother, physicians usually perform an ultrasound examination to determine fetal age, existence of multiple pregnancies and to view any obvious birth defects.²⁰² Following an ultrasound, the treating physician may perform amniocentesis to confirm a neural tube defect.²⁰³ In addition, it is possible to determine approximately twenty percent of unborn children with Down's Syndrome by following the above screening process. Low serum AFP values have been shown to be associated with fetal Down Syndrome.²⁰⁴

Maternal AFP testing has been used extensively in England since the 1970's, but has not been utilized in the United States due to the Food and Drug Administration's delay in approving the AFP test kits until 1983.²⁰⁵

After the Food and Drug Administration approved the AFP Kits, the American College of Obstetricians and Gynecologists (ACOG) issued a professional liability alert recommending that its members advise all prenatal patients of the availability of AFP testing.²⁰⁶ The ACOG alert has the effect of establishing evidence of the standard of care for obstetricians in negligent genetic counseling cases. The ACOG alert does not endorse AFP tests. It does suggest that obstetricians document that all prenatal patients have been advised of the availability of the test.

In 1986, California became the only state to require physicians to offer all prenatal patients the opportunity to undergo AFP testing. The California program has a statewide computerized data base, a standardized informed consent form, and eight laboratories regulated by the state to perform the AFP tests. The state has established eighteen prenatal counseling centers which may include ultrasound and amniocentesis.²⁰⁷ The program is designed to complete the counseling and diagnostic testing process by the twenty-fourth week of pregnancy which has been established by California as the outer limit for abortions.²⁰⁸

The California AFP testing program combined with the ACOG alert provides strong incentives for all physicians who treat pregnant women to advise of the availability of AFP testing. Most civilian hospitals quickly implemented AFP testing after the ACOG alert.

Genetic counseling diagnostic procedures have developed rapidly since amniocentesis was first used extensively in the late 1960's. Recently a new diagnostic procedure, chorionic villi sampling (hereinafter CVS) has been developed. The procedure is performed during the eighth to tenth week of gestation.²⁰⁹ Sufficient chorionic villi can be collected to permit direct biochemical analysis without the need for culturing. Therefore, the results of CVS are available within several days.²¹⁰

CVS has several advantages over amniocentesis. It can be performed in the first trimester of pregnancy and the results are available within several days. Amniocentesis is performed in the sixteenth week of gestation and it can take several weeks to obtain the results.²¹¹ CVS would give a family the alternative of electing to have an abortion earlier in the pregnancy. The family's concern regarding the possibility of a genetic disorder would be alleviated by the earlier diagnosis possible with CVS. One limitation of CVS is that it does not evaluate amniotic fluid so

the testing of alpha-fetoprotein levels to validate neural tube defects is not possible.

CVS is such a new procedure that the risks have not been clearly identified. Spontaneous abortion and infection appear to be the primary risks.²¹² CVS is being utilized by a few medical centers in the United States.²¹³ Although a new procedure, physicians will probably recommend CVS to patients who seek counseling early in their pregnancies and do not want to wait until amniocentesis is possible later in their pregnancies.

Most of the diagnostic procedures have some degree of risk to the mother and fetus and require the treating physician to obtain informed consent to the specific procedure. Physicians would also be prudent to begin the genetic screening process by the use of a questionnaire to document the patient's decision to participate in genetic counseling.²¹⁴ California has required physicians to complete a standardized informed consent form as a prerequisite for alpha-fetoprotein testing.²¹⁵ A physician's failure to obtain his patient's informed consent to a diagnostic procedure would be difficult to defend in combination with a spontaneous abortion which occurred following an invasive diagnostic procedure.

B. IN-UTERO DIAGNOSIS OF SPECIFIC GENETIC DISORDERS

There are approximately two hundred genetic diseases which can be diagnosed in-utero.²¹⁶ Genetic disorders are usually classified into single mutant gene disorders, chromosomal abnormalities, and multifactorial disorders. In single gene defects, the mutation can be present on only one chromosome of a pair or on both chromosomes. In either case, the defect is caused by one single error in the genetic information transmitted from the parents to the fetus. Single gene defects are rare, occurring in one in every two thousand births. Single gene defects occur in identifiable pedigree patterns in families which may be identifiable for generations.

Chromosome disorders are caused by an imbalance in genetic material. The imbalance may be caused by an excess or deficiency of whole chromosomes or chromosome segments. Chromosome disorders occur in about seven in one thousand births, but do not have the pedigree patterns of single gene defects.

Multifactorial inheritance disorders result from interactions between several genes and environmental factors. There is usually no one major error in the genetic information, but the combination of small variations creates a genetic disorder. Multifactorial disorders tend to occur repeatedly in families, but do not demonstrate the clear cut pedigree patterns of single gene disorders.²¹⁷

Single mutant gene disorders are further sub-divided into x-linked traits,²¹⁸ autosomal dominant traits,²¹⁹ and autosomal recessive trait disorders.²²⁰ X-linked diseases for which carrier testing is possible include hemophilia,²²¹ Fabry's disease,²²² and Duchenne muscular dystrophy.²²³

Autosomal recessive diseases which can be carrier tested include Tay-sachs disease,²²⁴ sickle-cell anemia,²²⁵ and cystic fibrosis.²²⁶ Autosomal dominant diseases for which pre-natal diagnostic is feasible include familial hypercholesterolemia²²⁷ and porphyrias.²²⁸

Chromosomal abnormalities can be divided into trisomies with three copies of a particular chromosome rather than two and monosomies, with one chromosome of a pair missing. The most common example of a chromosomal abnormality is Down's Syndrome.²²⁹

The most common examples of multifactorial diseases are clubfoot, cleft lip,²³⁰ and neural tube defects. Neural tube defects are further divided into anencephaly and spina bifida.²³¹

Researchers have not fully evaluated the effect of exposure to radiation, drugs, and viral agents. As genetic technology improves, future genetic counseling for teratogen exposure will greatly expand.²³² As more is learned about those effects, genetic counseling will be necessary to advise women of the risks of birth following teratogen exposure.

VI. CONFLICTS BETWEEN MOTHERS AND UNBORN CHILDREN

Another major problem confronting genetic counselors in military hospitals is the conflict, or potential conflict, between the mother and her unborn child. Physicians are now able to diagnose a large number of genetic disorders in-utero. Physicians can treat a few of these disorders in-utero. As the number of genetic disorders that can be treated in-utero increases, the potential conflicts between mother and child will increase. When prenatal drug therapy or surgery is contemplated, the mother must consent to the procedure and accept the medical risks without receiving any personal benefit. The unprecedented situation where the patient is located inside another person's body creates legal and ethical dilemmas. While most pregnant women will desire to aid in the birth of a healthy child, conflicts may arise. The mother has to make a subjective decision about the most appropriate course of treatment for her fetus. If the physician does not agree with the mother's decision he must decide whether he has a duty to the fetus independent from his duty to the mother.

In a similar situation, a physician may have to decide if he has an independent duty to a fetus when the mother exposes herself to teratogenic elements. Human teratogens can cause genetic disorders and fifty percent of pregnant women inadvertently expose themselves to teratogens after becoming pregnant.²³³ If a woman is purposely and repeatedly exposing herself to teratogens, the treating physician must decide if he has a duty to the unborn child when he knows the mother is endangering the fetus.

Physicians' duties to unborn children depend on the court's interpretation of the status of unborn children. The case of Dietrich v. Inhabitants of Northampton,²³⁴ established the precedent for over fifty years that a baby could not recover for prenatal injuries because the fetus was not a separate person at the time of the injury.²³⁵ The Dietrich precedent was overturned in Bonbrest v. Kotz²³⁶ when the Federal District Court for the District of Columbia ruled that a child could recover for a prenatal injury that occurred after viability. A New York court was the first court to allow a child to recover for prenatal injuries that occurred prior to viability.²³⁷ Currently, seventeen states allow a child to recover for prenatal injuries prior to viability while nineteen states allow recovery for post-viability injuries.²³⁸

Despite the fact that a child may recover for prenatal injuries that occur before birth, the Supreme Court has ruled that a fetus is not a person for federal constitutional purposes.²³⁹ States, however, still have legitimate interests in unborn children and state governments can regulate childbearing in a manner rationally related to a legitimate state interest.²⁴⁰

The Supreme Court has limited the discretion of states by giving the mother the right to abort a child in the first trimester. The Supreme Court actually gave the decision to abort the child to the physician in consultation with the mother.²⁴¹ The Court in Roe v. Wade held that a state's interest in regulating abortion becomes compelling at viability, which may occur as early as twenty-four weeks.²⁴² States may prevent a mother from aborting the child after viability unless the mother's life is in danger. Although the Supreme Court has steadfastly applied its Roe v. Wade viability standard, Justice O'Connor in her dissent in Akron v. Akron Center for Reproductive Health,²⁴³ stated that the viability standard was "on a collision course with itself"²⁴⁴ due to technological advances. The

viability question is important since a physician's duty to the fetus will depend on the state law which gives a fetus the right to sue for pre-viability torts.

The Supreme Court has not considered the duty of a physician to a fetus in its abortion decisions. Many courts have held that physicians have a duty to unborn children and to the parents of an unborn child to provide genetic counseling. There are no reported cases of a court ruling a physician has a duty to a fetus when a mother's conduct exposes the fetus to a teratogen or the mother refuses to consent to a medical procedure for the benefit of the fetus.

The few reported conflicts between mother and child have arisen in situations where physicians have requested court intervention to protect a fetus. The earliest cases involve mothers who refused medical treatment beneficial to an unborn child based on religious beliefs.²⁴⁵ Although the fourteenth amendment protects the fundamental right of free parental choice in family matters,²⁴⁶ courts often take temporary custody of children to order medical treatment.²⁴⁷

The Georgia Supreme Court became the first appellate court to affirm a trial court's decision to take custody of a fetus and order an unwilling mother to undergo blood transfusion, an ultrasound, and a cesarian section to save the life of a thirty-nine week old fetus.²⁴⁸ The mother objected to the cesarian section on religious grounds, but the court ordered the procedure since there was almost no chance the fetus would survive otherwise.²⁴⁹

The Georgia Supreme Court apparently based its decision on Georgia's juvenile statutes which allow the state to take custody of a child when the parents endanger the child.²⁵⁰ Other state courts have refused to extend the protection of juvenile or child abuse statutes to unborn children.²⁵¹

In a recent California case, a mother was criminally charged with fetal abuse for ingesting amphetamines during her pregnancy and disobeying instructions to seek medical attention if she began to hemorrhage as a result of her placenta separating from her uterine wall. Her son was born brain dead. She was charged with the misdemeanor of failing to provide medical treatment to her son under a section of the California code which defines a child conceived but not yet born as a person covered under the state child abuse statute.²⁵² While this case may be an aberration, the ability of physicians to link teratogen exposure to specific genetic disorders will cause physicians to monitor their patients' activities much more actively than in the past. The possibility of parents being charged with neglecting their unborn children may cause physicians to consider whether they have a duty to report such instances in the same manner they are required to report child abuse in most states.

Physicians may also have to consider their duties to unborn children as a result of the rapid advances in fetal surgery. While not accurately considered fetal surgery, the intentional early cesarian section due to a diagnosis by ultrasound or amniocentesis may benefit the fetus and is the most common method to aid a distressed fetus. Newer types of fetal surgery are now possible for a variety of diseases.²⁵³ Physicians will not often treat a mother who does not choose a medically indicated procedure for her fetus. When the situation does arise, the physician must decide if his patient is the mother or the fetus or both.

The possible conflict between the state's interest in the life of a fetus versus the mother's right of personal autonomy can create difficult alternatives for physicians and genetic counselors. When a family is presented with a diagnosis of an in-utero defect capable of surgical correction, the ultimate decision on a course of treatment rests with the mother. The Supreme Court recognized the state's interest to preclude

abortion in the third trimester except when necessary to preserve the life or health of the mother.²⁵⁴ In Colautti v. Franklin,²⁵⁵ the Supreme Court found a section of the Pennsylvania Abortion Control Act²⁵⁶ unconstitutionally vague because it did not clearly state that the woman's life and health must always prevail over the fetus' life and health when there is a conflict.

The Supreme Court has clearly established that a woman's constitutional right of privacy and her interest in her own health must prevail over the rights of a fetus. Despite the lower court rulings to the contrary, the decisions of the Supreme Court mandate conservative action by hospitals and physicians. No medical procedure for the benefit of the fetus should be performed without the mother's consent. If the mother does not consent, a physician's only alternative is judicial intervention.

VII. THE PRACTICE OF GENETIC COUNSELING IN MILITARY HOSPITALS

Military physicians at the military medical centers conduct genetic counseling in a fairly consistent manner as reflected in a survey of the military hospitals.²⁵⁷ Most of the medical centers have a staff perinatologist who conducts or supervises the genetic counseling program. Those medical centers where a perinatologist was not assigned, referred patients requiring genetics counseling to a nearby civilian medical center or to a nearby military medical center.²⁵⁸

The perinatologists who conduct genetic counseling at the medical centers are also responsible for providing assistance to smaller military hospitals in their geographical area. This is an analogous situation to smaller civilian hospitals. Physicians in smaller military hospitals also have the option of referring patients directly to civilian geneticists in their local area. How often this is done in small hospitals is uncertain since the

surveyed physicians indicated they do not often refer patients to civilian practitioners due to cost and convenience considerations.

Physicians in military medical centers are using ultrasound and amniocentesis as their primary diagnostic tools in genetic counseling. Military physicians, like their civilian counterparts, have abandoned amniography and fetography as diagnostic tools while chorionic villi sampling and fetoscopy have not become common procedures.²⁵⁹ The use of chorionic villi sampling and fetoscopy is not widespread, but patients who have desired early diagnosis of a possible genetic disorder have been referred to civilian centers, by their military physicians.

In response to the ACOG alert recommending that physicians offer AFP screening to patients,²⁶⁰ most military medical centers have begun AFP screening or will initiate it in the next several months. The initiation of AFP screening has been slow due to difficulties in obtaining funds to pay the approximately forty dollar per test laboratory fee.

Physicians at the five naval hospitals reported that AFP screening was currently being offered to all pregnant women. There are several Army hospitals that plan to offer AFP screening shortly and the physicians at those hospitals cited funding difficulties as the cause for the delay in implementation. The physicians at Eisenhower Army Medical Center and Wright Patterson Air Force Medical Center reported that AFP screening would not be implemented at their hospitals. At Tripler Army Medical Center, AFP screening is only offered to those women identified as high risk patients.²⁶¹

All surveyed physicians stated that their physicians screened patients according to the American Medical Association standards to determine which patients required referral to a genetic counselor. All physicians reported that the necessity for genetic counseling is documented during initial history and physical.

The surveyed physicians identified problem areas in their genetic counseling problems which were primarily related to the new AFP screening program. Several physicians reported problems in obtaining laboratory results in a timely manner. In addition, several physicians reported their laboratories are not reporting low AFP values which can be useful in detecting Down's Syndrome.

Physicians at the military hospitals where large numbers of deliveries are performed expressed concern at the increased genetic counseling workload which they expect as a result of AFP screening. The physicians expected their workloads to increase with the initial screening required for those women with abnormally high AFP values which may indicate neural tube defects and abnormally low AFP values which may indicate Down's Syndrome. Once the initial interviews have been conducted following AFP screening, most physicians expected their amniocentesis testing to increase as part of the normal three-part pattern of confirming AFP results by ultrasound and amniocentesis.

Many physicians expected their counseling programs to expand in the future as more heterosexual men and women are exposed to the Acquired Immune Deficiency Syndrome (hereinafter AIDS) virus. The estimates of vertical transmission of AIDS from mothers to children vary between 10% and 70% according to the surveyed physicians and many physicians expected their AIDS counseling programs to expand their counseling programs. The direct effect on genetic counseling programs would be an added time demand on trained counselors to counsel women with AIDS as well as parents requiring genetic counseling.

VIII. RECOMMENDATIONS

Military obstetricians can expect ever increasing demands for genetic counseling as a result of improved information from medical technology, increasing knowledge about the possibilities of fetal surgery, and the dangers of teratogen exposure. I recommend that military physicians require all patients complete a questionnaire answering basic questions about their family and personal history. This form would serve as documentation of the conversation between the patient and the physician who conducts the initial interview. The current practice of documenting the genetic counseling questions as part of the history and physical does not adequately protect either the United States as the defendant in a suit, nor the individual physician whose professional judgment may be questioned. Military physicians work in high volume practices and it is inevitable that physicians may forget or may not have time to document the initial genetic counseling interview. An example of a patient genetic counseling questionnaire is found in Williams Obstetrics.²⁶² I recommend this form be modified to include a patient's refusal to undergo AFP screening as reproduced at Appendix B.

I also recommend that a uniform policy for AFP screening be promulgated for all Department of Defense hospitals. The majority of military hospitals have implemented or plan to implement AFP screening. Given the fact that the American College of Obstetricians and Gynecologists issued a professional liability alert recommending that every pregnant woman be offered AFP screening, every military hospital should implement an AFP screening program. It would be very difficult to defend a suit for the birth of a child with a neural tube defect when no AFP screening was offered at a military hospital. Funding for the costs of AFP screening must be provided. Additional funds will be necessary for improvements in laboratory facilities which support military genetic counselors. Timely laboratory reports allow counselors to provide families with data prior to the time a fetus becomes viable.

Additional genetic counselors will be needed in military hospitals to meet the increasing demand for counseling as a result of AFP screening and the increasing numbers of genetic disorders which can be diagnosed in-utero. The increased demand for prenatal counseling as a consequence of AIDS will add to genetic counselors' workload.

Genetic counselors do not need to be physicians, but can be registered nurses who are trained registered genetic counselors. Trained nurses can perform the development of the family pedigree and review of the family's medical records, thus limiting the number of additional physicians who will be required to participate in the genetic counseling program. Presently, perinatologists at most military hospitals perform genetic counseling. Due to their primary responsibilities for management of high risk pregnancies, perinatologists cannot continue to perform all counseling and must be provided trained assistants.

The need for additional genetic counselors and additional funding to pay for AFP screening and laboratory testing is clear. The military faces a classic "pay now or pay later" situation with its genetic counseling program. If increased staffing and funding are not made available to support the genetic counseling program, there will be an increase in the number of tort claims and suits alleging negligent genetic counseling. If the United States is unable to successfully defend a relatively small number of genetic counseling suits, it has paid the costs of improved genetic counseling programs in damage awards to small numbers of patients rather than providing better counseling programs for large numbers of patients.

In addition to AFP screening, the Department of Defense needs to establish uniform policies for military hospitals and their genetic counseling programs. Issues involving pre-natal care and genetic counseling which require standard approaches include confidentiality of genetic

information, fetal surgery, and responses to new technology. Genetic information is typically limited to the immediate family, but standards are necessary to provide guidance to military physicians for those situations when genetic information can be released to third parties.

The increasing ability of physicians to perform fetal surgery has presented ethical questions. Physicians will be required to decide to whom they owe primary responsibility if the mother elects not to follow a course of treatment which would benefit her fetus. The Supreme Court's decision in Roe v. Wade makes clear the physician's primary responsibility is to the mother. When Roe v. Wade was decided in 1973, fetal surgery was not practiced to a significant degree. The Department of Defense should establish procedures to protect the fetus' interests as well as the mother's interests.

When a conflict between a mother and a fetus develops in a military hospital, the treating physicians should refer the case to the hospital ethics committee. If the conflict cannot be resolved after the family has had the opportunity to discuss the situation with the physicians, chaplain, attorney, and nurses who are the members of most military hospital ethics committees, the hospital must have a court appoint a guardian for the fetus. The guardian will then have to decide if court action is necessary on behalf of the fetus.

The military's relatively slow response to the alpha-fetoprotein screening program in the last two years indicates the need to establish uniform policies within the Department of Defense to respond to technological advances in genetic counseling. The next breakthroughs in genetic counseling appear to be chorionic villi sampling and fetoscopy. As these diagnostic procedures become more common in civilian hospitals, the military will have to decide if the procedures will be performed in military hospitals or if pregnant women will be reimbursed through CHAMPUS for these procedures.

IX. CONCLUSION

Genetic counseling has become increasingly sophisticated in the last thirty years. My intention in writing this article was to show how the rapid technological advances have improved physicians' abilities to predict genetic disorders in unborn children. Physicians have been able to provide better medical care to parents and unborn children with the newly developed diagnostic procedures. As those diagnostic procedures have become more common, the tort law has followed and created a new body of law with wrongful life and wrongful birth suits. Federal courts have been quick to accept wrongful birth suits, even in the absence of acceptance of such claims by state courts. Both state and federal courts are likely to continue to accept wrongful life and wrongful birth claims.

The Department of Defense must make a strong commitment to genetic counseling if obstetric care will continue to be offered in military hospitals. The primary goal of increased funding for genetic counseling should be improved medical care for military families with an attendant reduction in the number of children who are born with severe genetic disorders. A side effect of improved genetic counseling in military hospitals will be a reduced number of claims and lawsuits for wrongful life and wrongful birth.

FOOTNOTES

1. Spina bifida is a neural tube defect. The neural tube is the fetal precursor of the brain and spinal cord. Spina bifida is the failure of the fetal spinal column to close properly or to be absent entirely. Spina bifida is associated with mental and physical defects ranging in degree from mild to severe. Many of the more severe problems of spina bifida can be eased by surgery. Intensive rehabilitation can also alleviate the difficulties associated with problems such as mental retardation, lower limb paralysis, and lack of bowel and bladder control. See Nelson Textbook of Pediatrics, at 1561 (D. Behrman and V. Vaughn 12th ed., 1983) (hereinafter Nelson Pediatrics).
2. 28 U.S.C. §§ 1346(b), 2671-2680 (1982). The Federal Tort Claims Act waives the United States' sovereign immunity in tort cases.
3. Alpha-fetoprotein (AFP) is a substance which is thought to be involved in the fetal immunological system. Elevated AFP levels are associated with neural tube defects. AFP values can be tested initially by evaluating maternal blood. The two types of neural tube defects are anencephaly (brain or skull missing or incomplete) and spina bifida (spinal cord is missing or incomplete). Anencephaly and spina bifida occur in approximately 1 per 1000 live births in the U.S. Low AFP levels are associated with Down's Syndrome. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, The Ethical Social and Legal Implications of Genetic Screening, Counseling and Education Programs, at 26 (1983) (hereinafter President's Commission).
4. Amniocentesis is performed by inserting a long needle through the abdominal and uterine walls and withdrawing about 1/3 ounce of the

fluid surrounding the fetus. The amniotic fluid is centrifuged to isolate its component cells, compounded with calf serum, and then grown in a culture medium for two to four weeks. Amniocentesis is usually performed around the fifteenth or sixteenth week of pregnancy. Serious maternal or fetal complications associated with the procedure are less than .5%. See Nadler, Prenatal Detection of Genetic Defects, 74 J. Pediat. 132, 135 (1969); see also National Institute of Child Health and Human Development, Antenatal Diagnosis: Report of a Consensus Development Conference, Department of Health, Education and Welfare, at 66 (1979).

5. J. Thompson and M. Thompson, Genetics in Medicine, at 333 (4th ed. 1986).
6. Steele and Breg, Chromosome Analysis of Human Amniotic Fluid Cells, 1 Lancet 383 (1966).
7. Antenatal Diagnosis I, at 27-29 (U.S. Dept. of Health, Education and Welfare, 1979).
8. Harbeson v. Parke Davis, 746 F.2d 517 (9th Cir. 1984); Phillips v. United States, 508 F. Supp. 544 (D.S.C. 1981); Jacobs v. Theimer, 519 S.W.2d 846 (Tex. S.C. 1975).
9. Turpin v. Sortini, 31 Cal 3d 220, 643 P.2d 954 (Cal. 1982).
10. See 28 U.S.C. §§ 1346(b), 2671-2680 (1982).
11. Telephone interview with Mr. Joseph Rouse, Chief, General Claims Division, U.S. Army Claims Service (Jan. 8, 1987).

12. Robak v. United States, 658 F.2d 471 (7th Cir. 1981) (applying Ala. law); Harbeson v. Parke-Davis, 746 F.2d at 517 (applying Wash. law); Phillips v. United States, 575 F. Supp. 1309 (D.S.C. 1983) (applying S.C. law).
13. Robak, 658 F.2d at 474.
14. Holt, Wrongful Pregnancy, 33 S. C. L. Rev. 759 (1982).
15. President's Commission, at 26.
16. See J. Wyngaarden and L. Smith, Cecil Textbook of Medicine, at 122 (1985).
17. President's Commission, at Appendix B.
18. Principles and Practice of Medical Genetics 99 (A. Emery and D. Rimoin 4th ed. 1983). See also, J. Roberts, An Introduction to Medical Genetics, Chap. 12 (5th ed. 1970).
19. See supra text accompanying notes 6-7.
20. 410 U.S. 113 (1973).
21. Id. at 164.
22. Id. at 166; see also, Thornburgh v. American College of Obstetricians and Gynecologists, 106 S.Ct. 2169 (1986).
23. Turpin v. Sortini, 31 Cal.3d 220, 643 P.2d 954 (Cal. 1982).
24. Holt, Wrongful Pregnancy, 33 S. C. L. Rev. 759 (1982).

25. Zepeda v. Zepeda, 411 Ill. App. 2d 240, 190 N.E.2d 849 (1963) cert. denied, 379 U.S. 945 (1964). See also Comment 40 Mo. L. Rev. 167 (1979); Williams v. State of N.Y., 18 NY.2d 481, 223 N.E.2d (1966); Stills v. Gratlon, 55 Cal. App. 3d 698, 122 Cal. Rptr. 652 (1976).
26. Zepeda, 411 Ill. App.2d at 259, 190 N.E.2d at 858.
27. Id. at 262, 190 N.E.2d at 859.
28. Id.
29. 49 N.J. 22, 227 A.2d 689 (1967) (overruled in part by Berman v. Allan, 80 N.J. 421, 404 A.2d 8 (1979)).
30. Id. at 24, 227 A.2d at 691.
31. Id. at 24, 227 A.2d at 690.
32. Id. at 28, 227 A.2d at 692. The New Jersey Supreme Court reaffirmed its position in Gleitman 12 years later when a 38 year old pregnant woman was not told of the existence of amniocentesis and she delivered a daughter with Down's Syndrome. The court rejected the child's wrongful life claim. The court based its decision on the public policy basis that life with handicaps is more precious than non-life. The parents were allowed to recover for emotional distress. Berman v. Allen, 80 N.J. 421, 404 A.2d 8 (1979).
33. 60 A.D.2d 80, 400 N.Y.S.2d 110 (1977).
34. 46 N.Y.2d 401, 386 N.E.2d 807 (1978). (In Becker, the plaintiff mother was never advised of the availability of amniocentesis after

she became pregnant and she sued on her behalf for wrongful birth of her daughter, who was afflicted with Down's Syndrome, as well as filing a suit for wrongful life for her daughter.

35. Harbeson v. Parke-Davis, 746 F.2d 517 (9th Cir. 1984) (Wrongful life and wrongful birth suit allowed under Washington law in fetal hydantoin case); Scales v. United States, 685 F.2d 970 (5th Cir. 1982) rehear. den. 691 F.2d 602 (2nd Cir. 1982), cert. denied 460 U.S. 1082 (1985) (Infant's wrongful life suit barred as derivative claim from mother who was on active duty when alleged misdiagnosis of rubella occurred); Turpin v. Sortini, 182 Cal. Rptr. 337, 643 P.2d 954 (Cal. Sup. Crt. 1982) (Both wrongful life and wrongful birth allowed in congenital deafness case); Continental Gas Co. v. Empire Gas Co., 713 P.2d 384 (Col. App. 1985) (Both wrongful life and wrongful birth allowed in Colorado in RH incompatibility suit). See also Procanik v. Cillo, 97 N.J. 339 478 A.2d 755 (1984) (Wrongful life and wrongful birth claims allowed in New Jersey for failure to diagnose mother's rubella); Harbeson v. Parke-Davis, 98 Wash. 2d 460, 656 P.2d 483 (1983) (Wrongful life and wrongful birth cognizable in Washington).
36. Turpin v. Sortini, 31 Cal.3d, 220, 643 P.2d 954 (1982); Procanik v. Cillo, 97 N.J. 339, 478 A.2d (1984); Harbeson v. Parke-Davis, 98 Wash.2d 460, 656 P.2d 483 (1983). A Colorado appellate court allowed a child to maintain a wrongful life course of action for RH incompatibility. Continental Gas Co. v. Empire Gas Co. 713 P.2d 384 (Col. App. 1985).
37. Curlender v. Bio-Science Laboratories, 106 Cal. App. 3d 811, 163 Cal. Rptr. 477 (1980).
38. Id. at 832, 165 Cal. Rptr. at 489.

39. Turpin v. Sortini, 119 Cal. App. 3d 690, 174 Cal. Rptr. 128 (1981).
40. Turpin v. Sortini, 31 Cal.3d 220, 643 P.2d 954 (1982).
41. Id. at 239, 643 P.2d at 969.
42. California Civil Code § 43.6 (West 1982), provides:
- (a) No cause of action arises against a parent of a child based upon the claim that the child should not have been conceived or, if conceived, should not have been allowed to have been born alive.
 - (b) The failure or refusal of a parent to prevent the live birth of his or her child shall not be a defense in any action against a third party, nor shall the failure or refusal be considered in awarding damages in any such action.
 - (c) As used in this section, "conceived" means the fertilization of a human ovum by a human sperm.
43. 31 Cal.3d at 228, 643 P.2d at 959. See also Comment, 18 U.S.F.L. Rev. 77, 100 (1983) for a discussion of Cal. Civil Code § 43.6 (1982).
44. Call v. Kezirian, 135 Cal.App.3d 189, 185 Cal. Rptr. (1982); Andalon v. Superior Court, 298 Cal. Rptr. 899 (Ct. App. 1984).
45. Harbeson v. Parke-Davis, 98 Wash.2d 460, 656 P.2d 483 (1983).
46. Fetal hydantoin syndrome is a congenital abnormality characterized by growth deficiencies and developmental retardation. See S. Rudolph, Textbook of Pediatrics, at 156 (1982).
47. Harbeson, 98 Wash.2d at 463, 656 P.2d at 486-87 (1983).

48. Id. at 463, 656 P.2d at 486.
49. Id. at 473, 656 P.2d at 495.
50. Id. at 478, 656 P.2d at 499.
51. 97 N.J. 339, 478 A.2d 755 (1984).
52. Id. at 341, 478 A.2d at 756.
53. Id. at 341, 478 A.2d at 756.
54. Goldberg v. Ruskin, 113 Ill.2d 482, 449 N.E.2d 406 (1986); Smith v. Cote, 513 A.2d 341 (N.H. Sup. Ct. 1986); Azzolino v. Dinghelder, 315 N.C. 103, 337 S.E.2d 528 (1985), cert. denied 107 S. Ct. 131 (1986); A Colorado appellate court has allowed a wrongful life action in a pre-conception RH incompatibility case, but wrongful life suits have not been considered by the Colorado Supreme Court. Continental Cas Co. v. Empire Cas Co., 713 P.2d 384 (Colo. App. 1985).
55. S.D. Codified Laws Ann. §§ 21-55-1-4 (1982); Minn. Stat. Ann. 145.424(1) (West 1983).
56. Parker, Wrongful Life: The Child's Cause of Action for Negligent Genetic Counseling in Texas, 16 St. Mary's L.J. 639 (1985); Steinbrook, The Logical Case for Wrongful Life, 16 Hastings Ctr. Rpt. 2:15 (April 1986); Wagner, Wrongful Life: Is Denial of this Cause of Action Consistent with Current Tort Law? 1983 Med. Trial Tech. Q. 137.
57. Robak v. United States, 658 F.2d 471 (7th Cir. 1981) (Under Alabama law, parents had wrongful birth cause of action for physician's failure

to warn parents of effect of mother's rubella on fetus); *Gallagher v. Duke University*, 638 F. Supp. 979 (M.D.N.C. 1986) (Wrongful birth suit cognizable in N.C. for negligent pre-conception counseling, distinguishing *Azzolina v. Dingfelder*, 318 N.C. 103 (1985); *Phillips v. United States*, 575 F. Supp. 1309 (D.S.C. 1983) (Wrongful birth suit allowed under South Carolina law for Down's Syndrome child). See also, *Phillips v. United States*, 566 F. Supp. 1 (D.S.C. 1981); *Phillips v. United States*, 508 F. Supp. 544 (D.S.C. 1980); *Phillips v. United States*, 508 F. Supp. 537 (D.S.C. 1980) (Wrongful life suit not recognized in South Carolina); *Gildiner v. Thomas Jefferson Memorial Hospital*, 451 F. Supp. 692 (E.D.PA 1978) (Wrongful birth suit allowed but not wrongful life suit in alleged negligent diagnosis of Tay-Sachs disease); *Elliott v. Brown*, 361 So.2d 546 (Al.S.C. 1978) (No legal right not to be born recognized in suit styled as wrongful life suit although court characterized as wrongful conception suit); *D. Natale v. Zieberman*, 409 So.2d 512 (Fl. Ap. 1982) (Wrongful birth cognizable in Florida, but not wrongful life); *Blake v. Cruz*, 108 Id 253, 693 P.2d 315 (1984) (Wrongful birth allowed but not wrongful life in Idaho, for physician's failure to diagnose mother's rubella); *Goldberg v. Ruskin*, 113 Ill.2d 482, 499 N.E.2d 406 (1986) (Negligent preconception counseling wrongful birth allowed, but not wrongful life); *Bruggeman v. Schimke*, 239 Kan. 245, 718 P.2d 635 (1986) (Wrongful birth recognized, but not wrongful life in alleged negligent preconception genetic counseling); *Strohmaier v. Associates in Obstetrics and Gynecology*, 122 Mich. App. 116, 332 N.W.2d 432 (1982); *Hickman v. Group Health Plan Inc.*, 396 N.W.2d 10, 55 U.S.L.W. 2240 (Minn. Sup. Ct. 1986) (Minn. stat. prohibiting wrongful life and wrongful birth suits constitutional); *Miller v. Duhant*, 637 S.W.2d 183 (Mo. App. Ct. 1982) (Wrongful life not cognizable in Missouri and wrongful birth claim in this case deemed to be wrongful conception claim); *Smith v. Cote*, 513 A.2d 341, 55 U.S.L.W. 2071 (N.H. Sup. Ct. 1986) (Wrongful birth cognizable in New Hampshire but not wrongful life); *Azzolino v.*

Dinghelder, 315 N.C. 103, 337 S.E.2d 528 (1985), cert. denied, 107 S.Ct. 131 (1986) (Court ruled neither wrongful life nor wrongful birth allowed in N.C. absent legislative action); Rubin v. Hamot Med. Ctr., 329 Pa. Sup. Ct. 439, 478 A.2d 869 (1984) (Wrongful birth cognizable in Pennsylvania but not wrongful life in Tay-Sachs case); Nelson v. Krusen, 678 S.W.2d 918 (Tx. Sup. Ct. 1984) (Wrongful life not recognized while wrongful birth claim, although recognized in Texas, barred by statute of limitations in Duchenne muscular dystrophy case); Nacash v. Burger, 223 Va. 406, 290 S.E.2d 825 (1982) (Wrongful birth claim allowed for negligent amniocentesis); Caserta v. Kirdnal, 332 S.E.2d 872 (W.Va. S. Ct. 1985) (Parents may maintain action for wrongful birth in West Virginia but child's action for wrongful life not recognized); Dumer v. St. Michaels Hospital, 69 Wis.2d 766, 233 N.W.2d 372 (1975) (Wrongful birth action, but not wrongful life allowed in Wisconsin in rubella case).

58. Harten v. Coons, 502 F.2d 1363 (10th Cir. 1974); White v. United States, 510 F. Supp. 146 (D. Kan. 1981); LaPoint v. Shirley, 409 F. Supp. 118 (W.D. Tex. 1976); Bishop v. Byrne, 265 F. Supp. 460 (S.D. W.Va. 1967); Custodio v. Bauer, 251 Cal. App. 2d 303, 59 Cal. Rptr. 463 (1967); Fassoulos v. Ramey, 450 So.2d 822 (Fla. Ct. App. 1984); Maggard v. McKelvey, 627 S.W.2d 44 (Ky. 1981); Pierce v. Piver, 45 N.C. App. III, 262 S.E.2d 320 (1980); Ball v. Mudge, 64 Wash.2d 247, 391 P.2d 201 (1964); Beardsley v. Wierdsma, 650 P.2d 288 (Wyo. 1982).
59. Boone v. Mullendre, 416 So.2d 718 (Al. 1982); Wilber v. Kerr, 275 Ark. 239, 628 S.W.2d 568 (1982); Super. Ct. Mingsbury v. Smith, 122 N.H. 237, 442 A.2d 1003 (1982); Schork v. Huber, 648 S.W.2d 861 (Ky. 1983); Mason v. Western Pennsylvania Hospital, 449 Pa. 484, 453 A.2d 974 (1982); Sala v. Tomlinson, 73 A.D.2d 724, 422 N.Y.S.2d 506 (1979); Rieck v. Medical Protective Co., 64 Wis.2d 514, 219 N.W.2d 242 (1974); McKernan v. Anheim, 102 Wash.2d 411, 687 P.2d 850 (1984); Beardsley v. Wierdsma, 650 P.2d 288 (Wyo. 1982).

60. Boone v. Mullendre, 416 So.2d 718, 721 (Ala. 1982); Rieck v. Medical Protective Co., 64 Wisconsin 2d 514, 517 219 N.W.2d 242, 244 (1974).

61. The benefits offset rule under Restatement (Second) of Torts 920 (1979):

When the defendant's tortious conduct has caused harm to the plaintiff or to his property and in so doing had conferred a special benefit to the interest of the plaintiff that was harmed, the value of the benefit conferred is considered in mitigation of damages, to the extent that this is equitable.

See also, Comment, Judicial Limitations on Damages Recoverable for the Wrongful Birth of a Healthy Infant, 68 Va. L. Rev. 1311 (1982).

62. Hartke v. McKelaway, 702 F.2d 1544 (D.C. Cir. 1983), cert. denied 406 U.S. 983 (1983).

63. Gleitman v. Cosgrove, 49 N.J. 22, 227 A.2d 689 (1967).

64. Id. at 30, 227 A.2d at 693.

65. Stewart v. Long Island College Hospital, 58 Misc.2d 432, 296 N.Y.S. 41, modified 35 A.D.2d 531, 313 N.Y.S.2d (1970), aff'd. mem. 30 N.Y.2d 695, 293 N.E.2d 616 (1972).

66. Jacobs v. Theimer, 519 S.W.2d 846 (Tex. 1975).

67. Id. at 849.

68. Gildiner v. Thomas Jefferson University Hospital, 451 F. Supp. 692 (E.D. Pa. 1978); Becker v. Schwartz, 46 N.Y.2d 401, 386 N.E.2d 807, 413 (1978); Dumer v. St. Michael's Hospital, 69 Wis.2d 766, 233 N.W.2d 372.

69. 80 N.J. 421, 404 A.2d 8 (1979).
70. 87 N.J. 53, 432 A.2d 834 (1981).
71. Robak v. United States, 658 F.2d 471 (7th Cir. 1981); Phillips v. United States, 508 F. Supp. 544 (D.S.C. 1981).
72. Robak v. United States, 658 F.2d 471 (7th Cir. 1981).
73. Id. at 478.
74. 98 Wash.2d 460, 656 P.2d 483 (1983).
75. Id. at 470, 656 P.2d at 494.
76. See supra note 57.
77. Jacobs v. Theimer, 519 S.W.2d 846 (Tex. 1975).
78. Schroder v. Perkel, 80 N.J. 421, 404 A.2d 8 (1979).
79. Robak v. United States, 658 F.2d 471 (7th Cir. 1981).
80. White v. United States, 510 F. Supp. 146 (D. Kan. 1981); Custodia v. Bauer, 251 Cal. App.2d 303, 59 Cal. Rptr. 463 (1967).
81. Miller v. Johnson, 343 S.E.2d 301 (Va. Sup. Ct. 1986).
82. See supra notes 50-53 and accompanying text.
83. Harbeson v. Parke-Davis, 98 Wash.2d 640, 638 P.2d 483 (1983).

84. Steinbock, "The Logical Case for Wrongful Life," 16 Hastings Center Report 2:15 (April 1986).
85. F. Rouse, "The Physician and the Hopelessly Ill Patient," at Appendix A (1985).
86. Dep't. of Army, Reg. No. 40-3 Medical, Dental, and Veterinary Care, para. 19-1 - 19-9 (15 Feb 1985) (hereinafter AR 40-3). Dep't of Navy Letter MEDCOM-03C5420, subject: Guidelines for Orders not to Resuscitate, 24 April 1984. The Air Force directs physicians to follow local state laws for DNR and no code orders. Telephone interview with LTC R. Rhode, Office of the Surgeon General, USAF (4 Mar. 1987).
87. Tune v. Walter Reed Army Medical Center, 602 F. Supp. 1452 (D.C. 1985). See generally Barber v. Superior Court of California, 147 Cal. App.3d 1006, 195 Cal. Rptr. 484 (1983); Superintendent of Belchertown State School v. Saikewica, 373 Mass. 728, 370 N.E.2d 417 (1977) In Re Torres, 357 N.W.2d 332 (Minn. Sup. Ct. 1984); In Re Quinlan, 137 N.J. Super 227, 348 A.2d 801 (1975) mod. and remd. 70 N.J. 10, 355 A.2d 647, cert. denied 429 U.S. 922 (1976); In re Colyer 99 Wash.2d 114, 660 P.2d 738 (1983), over'd in part, In re Guardianship of Hamlin, 102 Wash.2d 810, 689 P.2d 1372 (1984).
88. Dep't of Army Ltr, DASG-PSQ, subject: Withdrawal of Life Support, 30 Aug 1985.
89. In re Treatment and Care of Infant Doe, No GU8204-004A (Cir. Ct., Monroe County, Ind. Apr. 12, 1982), writ of mandamus dismissed sub nom, Infant Doe v. Baker, No. 482-5-140 (Ind. May 27, 1982), cert denied sub nom. Doe v. Bloomington Hosp., 104 S.Ct. 394 (1983) (The suit became moot when Baby Doe died).

90. 29 U.S.C. § 794 (1982). The DHHS letter to hospitals is reprinted in 47 Fed. Reg. 26,027 (1982). The letter stated that it was unlawful under section 504 to deny a handicapped infant nutrition if the denial is based on existence of a handicap and the handicap does not render treatment or nutritional sustenance medically contraindicated.
91. 48 Fed. Reg. 9630 (1983) (modifying 45 C.F.R. § 84.61). The rule was declared invalid based on administrative procedural grounds shortly after its promulgation. *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395 (D.D.C. 1983); see also *United States v. University Hospital, State University of N.Y. at Stony Brook*, 729 F.2d 144 (2nd Cir., 1984).
92. 45 C.F.R. § 84.55 (1985).
93. *Bowen v. American Hospital Association*, 106 S.Ct. 2101 (1986).
94. Id. at 2112.
95. Id. at 2115-18.
96. 28 U.S.C. § 1346(b) (1982).
97. 451 F. Supp. 692 (E.D. Pa. 1978).
98. Id. at 696.
99. 508 F. Supp. 537 (D.S.C. 1980).
100. Id. at 544.

101. Phillips v. United States, 508 F. Supp. 544 (D.S.C. 1981).
102. Id. at 549-552.
103. Phillips v. United States, 566 F. Supp. 1 (D.S.C. 1981).
104. Id. at 1320.
105. 658 F.2d 471, 478 (7th Cir. 1981).
106. Id. at 473.
107. 746 F.2d 517 (9th Cir. 1984).
108. Harbeson v. Parke-Davis, 98 Wash. 2d 460, 656 P.2d 483 (1983).
109. 746 F.2d at 523.
110. 638 F. Supp. 979 (M.D. N.C. 1986).
111. 315 N.C. 103, 337 S.E.2d 528 (1985).
112. Id. at 112, 337 S.E.2d 536.
113. Feres v. United States, 340 U.S. 135 (1950).
114. United States v. Shearer, 473 U.S. 52 (1985); Beaucoudray v. United States, 490 F.2d 86 (5th Cir. 1974).
115. Stencel Aero Engineering Corp. v. United States, 431 U.S. 666 (1977). Van Sickel v. United States, 285 F.2d 87 (9th Cir. 1960).

116. *Scales v. United States*, 685 F.2d 970 (5th Cir. 1982), rehearing denied, 691 F.2d 502 (5th Cir. 1982) cert denied 460 U.S. 1082 (1983).
117. *Monaco v. United States*, 661 F.2d 129 (9th Cir. 1981) cert denied 456 U.S. 989 (1982).
118. 729 F.2d 1120 (7th Cir. 1984).
119. Id. at 1128.
120. *West v. United States*, 744 F.2d 1317 (7th Cir. 1984) cert denied 471 U.S. 1053 (1985).
121. 624 F. Supp. 641 (S.D. Ind. 1985).
122. Id. at 645.
123. *Heath v. United States*, 633 F. Supp. 1340 (E.D. Cal. 1986).
124. Id. at 1342.
125. 340 U.S. 135 (1950); *United States v. Shearer*, 473 U.S. 52 (1985); *Beaucoudray v. United States*, 490 F.2d 86 (5th Cir. 1974).
126. 804 F.2d 561 (9th Cir. 1986).
127. Id. at 564.
128. 473 U.S. 52 (1985) quoted in *Atkinson*, 804 F.2d at 566.
129. 804 F.2d at 566.

130. Id. at 565.
131. Robinson, 49 Law and Contemporary Problems 173 (1986). Several states have adopted a reasonable prudence standard of care for health care providers that may not always accept the customs of the medical profession as being reasonably prudent care. See Rowland v. Christian, 69 Cal.2d 108, 443 P.2d 561 (1968); Helling v. Carey, 83 Wash.2d 514, 519 P.2d 981 (1974).
132. See supra note 35.
133. See supra note 36.
134. Telephone interview with Ms. Jane Soloman, American Board of Genetics (Feb. 19, 1987).
135. Council on Scientific Affairs of the American Medical Association, Genetic Counseling and Prevention of Birth Defects, reprinted in 248 JAMA 221 (July 9, 1982); see also, J. Pritchard, P. MacDonald, and N. Gant, Williams Obstetrics (17th ed. 1985) (hereinafter Williams Obstetrics).
136. J. Thompson and M. Thompson, Genetics in Medicine, at 300-302 (1986).
137. Williams Obstetrics, at 275.
138. R. Skinner, Principles and Practice of Medical Genetics, at 1435 (1983) (hereinafter Skinner).
139. Id.

- 140. Id. at 1434.
- 141. Id.
- 142. Gildiner, 451 F. Supp. at 695; Phillips, 508 F. Supp. at 542.
- 143. Robak v. United States, 658 F.2d 471 (7th Cir. 1981).
- 144. Park v. Chessin, 400 N.Y.S.2d 110 (1977).
- 145. Wilson v. Gilbert, 25 Cal. App. 2d 607, 102 Cal. Rptr. 31 (1972);
Richardson v. Holmes, 525 S.W.2d 293 (Tex, 1975).
- 146. Telephone interview with Ms. Karen King, OCHAMPUS, Aurora,
Colorado (Feb. 18, 1987).
- 147. Salgo v. Leland Stanford Jr. University Board of Trustees, 154 Cal.
App. 2d 560, 317 P.2d 170 (1957).
- 148. Natanson v. Kline, 186 Kan. 393, 350 P.2d 1093, opinion on den'l of
rehearing 187 Kan. 186, 354 P.2d 670 (1960).
- 149. President's Commission for the Study of Ethical Problems in
Medicine and Biomedical and Behavioral Research Volume I, The
Ethical and Legal Implications of Informed Consent in the Patient-
Practitioner Relationship, at 206-251 (1982).
- 150. Id. See also Deardorff, Informed Consent, Termination of Medical
Treatment and the Federal Tort Claims Act - A New Proposal for
the Military Health Care System, 115 Mil. L. Rev. 1 (1987).

151. Canterbury v. Spence, 464 F.2d 772 (D.C. Cir. 1972); Cobbs v. Grant, 104 Cal. Rptr. 505, 502 P.2d; Sard v. Hardy, 281 Md. 4321, 379 A.2d 1014 (1977); Bertsch v. Brewer, 96 Wash.2d 973, 640 P.2d 711 (1982).
152. President's Commission, at 76.
153. President's Commission, at 78.
154. President's Commission, at 81.
155. Council on Scientific Affairs of the American Medical Association, Genetic Counseling and Prevention of Birth Defects, reprinted in 248 JAMA 221 (Jul. 9, 1982).
156. Harbeson v. Parke-Davis, 98 Wash.2d at 467, 656 P.2d at 491 (1983).
157. Horne v. Patton, 391 Ala 701, 287 So.2d 824 (1973); Simonsen v. Swenson, 104 Neb. 224, 177 N.W. 831 (1920).
158. Cal. Evid. Code § 990-1007 (West 1980).
159. Manual for Courts-Martial, United States, 1984, Mil. R. Evid. 501(d).
160. Slakan v. Porter, 737 F.2d 1187 (2d Cir. 1983); United States v. Meagher, 531 F.2d 752 (5th Cir. 1976) cert. denied 429 U.S. 853 (1976); United States v. University Hospital, 575 F. Supp. 602 (E.D.N.Y. 1983), but see In re Zuniga, 714 F.2d 632 (6th Cir. 1984) (Some federal courts recognize a patient-psychotherapist privilege).
161. Ga. Code Ann. § 31-12-1-31-33-6 (1986), see generally, George Washington University Intergovernmental Health Policy Project Review of State and Local Government Initiatives Affecting AIDS (1985).

162. 17 Cal.3d 425, 551 P.2d 334 (1976). The California Supreme Court originally held psychotherapists owe a duty of care to third parties threatened by their patients in *Tarasoff v. Regents of the University of California*, 13 Cal.3d 177, 529 P.2d 553 (1974). The original decision by the California Supreme Court was later vacated.
163. 17 Cal.3d at 431, 551 P.2d at 340.
164. *Jablonski v. United States*, 712 F.2d 391 (9th Cir. 1983), *Brady v. Hopper*, 570 F. Supp. 1333 (D. Colo. 1983); *Thompson v. County of Alameda*, 27 Cal.3d 741, 614 P.2d 728 (1980); *McIntosh v. Milano*, 168 N.J. Super. 466, 403 A.2d 500 (1979); *Peterson v. State*, 100 Wash.2d 421, 671 P.2d 230 (Wash. 1983).
165. *Lipari*, supra 497 F. Supp. at 193; *Peterson*, supra 100 Wash.2d at 428, 671 P.2d at 237.
166. Telephone interview with Ms. Debbie Eunpu, President, National Society of Genetic Counselors (Feb. 26, 1987).
167. *Gammill v. United States*, 727 F.2d 950 (10th Cir. 1984); *Davis v. Rodman*, 147 Ark. 385, 227 S.W. 612 (1921); *Wojeik v. Aluminum Co. of America*, 18 Misc.2d 740, 183 N.Y.S.2d 351 (1959).
168. *Gammill v. United States*, 727 F.2d 950 (10th Cir. 1984).
169. Id. at 954.
170. Id.
171. Id.

172. See, supra note 125 and accompanying text.
173. Diamond, Genetic Testing in Employment Situations, 4 J. Leg.Med. 231, 234 (1983).
174. Farrall and Scramber, Cystic Fibrosis Detection Using a Linked Gene Probe, 23 J. Med. Gen. 295 (1986).
175. Williams Obstetrics, at 278.
176. Id.
177. Freeman, J. ed. Prenatal and Perinatal Factors Associated with Brain Disorders, Hobel, T. Factors During Pregnancy that Influence Brain Development, p. 217. U.S. Department of Health and Human Services (1985) (hereinafter Freeman).
178. Williams Obstetrics, at 278-279. Ultrasonography can be used to diagnose intrauterine pregnancy, size and rate of growth of amnionic sac, identification of multiple fetuses, detection of fetal anomalies, such as polycystic kidneys, congenital heart disease, intestinal obstruction, and observation of maturity of the placenta.
179. J. Jule and L. Paul, Essentials of Roentgen Interpretation, at 9 (4th ed. 1981) [hereinafter Jule and Paul]. The recommended maximum maternal exposure to x-rays is 500 millirads for a 40 week pregnancy. An abdominal x-ray exposes the fetus to 221 millirads of radiation. Nelson Pediatrics, at 317.
180. Williams Obstetrics, at 279.

181. Williams Obstetrics, at 279.
182. Williams Obstetrics, at 280.
183. Jule and Paul, at 9.
184. Freeman, at 214.
185. Alpha-1 anti-trypsin deficiency is a blood serum deficiency which can lead to the early onset of emphysema. R. Petersdorf, R. Adams, E. Braunwald, K. Isselbacher, J. Martial and J. Wilson, Harrison's Principles of Internal Medicine, at 1236 (10th ed., 1983) (hereinafter Harrison's).
186. Chronic granulomatous disease is an inherited disease caused by staphylococci and gram negative bacteria which results in severe recurrent infections of the skin, lymph nodes, lungs, liver, and bones. Harrison's, at 307.
187. Hemoglobinopathies are deficiencies of the red blood cells. Sickle-cell anemia is the most prevalent form. About .15 percent of the black children in the United States have the disease. Harrison's, at 313 and 1876.
188. Hemophilia is a bleeding disorder caused by an inherited deficiency in the procoagulant activity of factor VIII, the antihemophilic factor. Hemophilia occurs in 1 in 10,000 people. Harrison's, at 1900.
189. Homozygous Von Willebrand's disease is a hereditary hemorrhagic disorder characterized by a prolonged bleeding time. Harrison's, at 1902.

190. Elias, Fetoscopy in Prenatal Diagnosis, 4 Semin. Perinatal 199-205 (1980).
191. Id.
192. Rodeck and Nicolaides, The Use of Fetoscopy for Prenatal Diagnosis and Treatment, 7 Semin. Perinatol. 118-124 (1983). Fetal blood loss, amnionitis, fetal maternal transfusion, and Rh isoimmunization are also risks of fetoscopy.
193. Freeman, at 214.
194. See supra note 4 for description of amniocentesis.
195. Williams Obstetrics, at 275.
196. It is estimated that ninety percent of all amniocentesis procedures are performed on women aged thirty-five or older. Hook, Rates of Chromosomal Abnormalities at Different Maternal Ages, 58 Obstet. Gynec. 282-285 (1981).
197. See supra note 100.
198. Williams Obstetrics, at 276.
199. Elevated alpha-fetoprotein levels can indicate the fetus has a neural tube defect, congenital nephrosis, bladder neck obstruction, or low birth weight. Williams Obstetrics at 277.
200. NICHD National Registry for Amniocentesis Study Group. Mid-trimester Amniocentesis for Prenatal Diagnosis: Safety and Accuracy, 26 J. Am. Med. A. 1471-76.

201. Id.
202. Jalms and Alpert, Results and Benefits of a Maternal Serum Alpha-fetoprotein Screening Program, 252 J. Am. Med. A. 1438-42 (1984).
203. Id.
204. Cuckle, Wald, and Lindenbaum, Maternal Serum Alpha-fetoprotein Measurement: A Screening Test for Down Syndrome, 1 Lancet, 926-29 (1984).
205. Annas, Is a Genetic Screening Test Ready when the Lawyers Say It Is? 15 Hastings Center Rep. 4:16 (December 1985).
206. The ACOG Department of Professional Liability alert is as follows:

Now that alpha-fetoprotein (AFP) test kits have been approved by the Food and Drug Administration (FDA) and are becoming more widely available, some professional liability implications should be kept in mind.

It is now imperative that you investigate the availability of these tests in your area and familiarize yourself with the procedure, location, and mechanism of the follow-up tests to screen for neural tube defects. It is equally imperative that every prenatal patient be advised of the availability of this test and that your discussion about the test and the patient's decision with respect to the test be documented in the patient's chart. This discussion would include the information you have discovered about availability, location, and mechanism of follow-up tests to screen for neural tube defects in the event of positive AFP results . . .

With the availability of prenatal testing for the rare but tragic circumstances of the birth of a child with a neural tube defect, it is important that patients be appropriately counseled. The physician who has fully discussed AFP tests and follow-up testing with his or her patients, who has let the patient make the decision, and who has documented it in the chart should be in the best possible defense position.

ACOG Department of Professional Liability, May 1985.

Id. at 17.

207. Steinbrook, Voluntary Mass Prenatal Screening (in California), 16 Hastings Ctr Rep. 12:5 (September 1986).
208. Id. at 6.
209. Simoni, Brambati, and Danesino, Efficient Direct Chromosome Analysis and Enzyme Determinations in the First Trimester of Pregnancy. 63 Human Genetics 349-357 (1983) In a CVS procedure, a physician using ultrasound for guidance, inserts a flexible suction catheter into a woman's vagina through the cervical canal to the placenta. Samples of fetal chorionic villi are collected in a syringe.
210. Pergament, Ginsberg, and Verlinski, Prenatal Tay-Sachs Diagnosis by Chorionic Villi Sampling, 2 Lancet 286 (1983).
211. See supra note 4.
212. Gregg, Alternative to Amniocentesis: CVS Gaining Acceptance, Washington Post Health Section, at 17 (December 16, 1986).
213. Id.
214. Williams Obstetrics, at 805-07.
215. See supra note 205.
216. Kolata, Genetic Screening Raises Questions for Employers and Insurers, 232 Science 317 (1986).

217. F. Fraser and J. Nora, Genetics of Man, at 76-96 (1986) (hereinafter Fraser); see also, Nelson Pediatrics, at 286-93 (12th ed. 1983). See generally, Thompson Genetics; Williams Obstetrics, at 798; C. Kempe, H. Silver, and D. O'Brien, Pediatric Diagnosis and Treatment, at 934 (1982).
218. Fraser, at 79. The 23rd pair of chromosomes, the sex chromosomes, differ in males and females. Women have two x chromosomes and they can be recessive carriers for all x-linked diseases.
219. Fraser, at 84. Autosomal dominant diseases are caused by mutation in one of the paired genes (alleles) on the twenty-two pairs of autosomal chromosomes. The gene mutation which affects a person's health or appearance is called a dominant gene mutation.
220. Fraser, at 84. An autosomal recessive disease is caused when both parents have the identical recessive gene mutation.
221. Hemophilia is a bleeding disorder caused by inherited deficiencies of coagulation factors. Harrison's, at 1900.
222. Fabry's Disease is an inherited disorder which occurs primarily in males. It is a disorder of lipid metabolism and death often occurs from renal failure. Harrison's, at 566.
223. Duchenne Muscular Dystrophy is characterized by progressive weakness and degeneration of muscle fibers in males. Most patients are confined to wheelchairs by age twelve. Harrison's, at 2188.
224. Tay Sach's disease is a disease of progressive mental retardation which is most common in Eastern European Jews. The disease is

caused by a deficiency of the enzyme hexosaminadase A. Harrison's, at 565.

225. Sickle-cell anemia is a chronic hemolytic anemia which occurs primarily in blacks. Afflicted individuals have a life expectancy of forty years. Harrison's, at 1877.
226. Cystic fibrosis is an inherited disease of the exocrine glands and eccrine sweat glands which primarily affects the digestive and respiratory systems. Cystic fibrosis has a one-in-four chance of occurring in children when both parents are carriers. Harrison's, at 1542 and 1844. See also, Farall and Scrambler, Cystic Fibrosis Carrier Detection Using A Linked Gene Probe, 23 Journal Med. Genetics 295-99 (1986) (Discussion of prenatal diagnosis of cystic fibrosis).
227. Hypercholesterolemia is a condition caused by abnormal levels of serum cholostorol. Harrison's, at 920.
228. Porphyrrias is a group of diseases in hemebiosynthesis which are caused by gene mutations. The Porphyrrias diseases decrease enzyme activity. Harrison's, at 533.
229. Fraser, at 32-40. Children with Down's Syndrome (Trisanyzl) have varying levels of mental retardation and difference physical handicaps. See also Nelson Pediatrics, at 295.
230. Fraser, at 90.
231. Id.

232. King, Genetic Counseling for Teratogen Exposure, 67 OB/GYN 843 (1986).
233. Id.
234. 138 Mass 14 (1884).
235. Id. at 15.
236. 65 F. Supp. 138 (D.D.C. 1946).
237. Kelly v. Gregory, 282 A.D. 542, 125 N.Y.S.2d 696 (1953).
238. Collins, An Overview and Analysis: Prenatal torts, preconception torts, Wrongful Life, Wrongful Death, and Wrongful Birth. Time for a New Framework, 22 J. Fam. L. 677 (1984).
239. Roe v. Wade, 410 U.S. 113 (1973).
240. Id. at 163.
241. Id. at 163.
242. Id. at 160.
243. 462 U.S. 416 (1983).
244. Id. at 458.
245. People ex rel. Wallace v. Labrenz, 411 Ill. 618, 104 N.E.2d 769 (1952); Jehovah's Witnesses v. King County Hospital, 278 F. Supp. 488 (W.D. Wa. 1967); Raleigh Fitkin-Paul Morgan Memorial Hospital

- v. Anderson, 42 N.J. 421 ,201 A.2d 537 cert. denied 377 U.S. 985 (1964).
246. Wisconsin v. Yoder, 406 U.S. 205 (1972); Prince v. Massachusetts, 321 U.S. 158 (1944); Meyer v. Nebraska, 262 U.S. 390 (1923).
247. Custody of a minor, 375 Mass 733, 379 N.E.2d 1053 (1978), In re Hudson, 13 Wash. 2d 673, 126 P.2d 765 (1942).
248. Jefferson v. Griffin Spalding County Hospital Authority, 247 Ga. 86, 244 S.E.2d 457 (1981).
249. 247 Ga. at 86, 274 S.E.2d at 457 (The mother was suffering from placenta previa in which the placenta partially or completely blocks the birth canal.)
250. 247 Ga. at 92, 274 S.E.2d at 464. See also, In re Baby Jeffries, No. 14004 (Jackson County P. Ct. Mich. May 24, 1982).
251. In re Stevens, 126 Cal. App. 3d 23, 178 Cal. Rptr. 525 (1981); Taft v. Taft, 446 N.E.2d 395 (Mass. 1983); Mercy Hosp. Inc. v. Jackson, A.2d (Md. 1955); In re Dittrick Infant, 80 Mich. App. 219, 263 N.W.2d 37 (1977).
252. American Medical News, Jan. 2, 1987, at 23, col. 1.
253. Fetal surgery is possible for obstructive uropathy which can be treated by placing a catheter into the fetal bladder to drain urine into the amniotic fluid. If a urethral obstruction requires surgery it is possible to partially remove the fetus, correct the abnormality, and replace the fetus in the uterus. Harrison and Golbus, Fetal Surgery for Congenital Hydronephrosis, 306 N. Eng. J. Med. 591

(1981). Congenital hydrocephalus which is blockage of the cerebrospinal fluid can cause retardation, nerve destruction, and cerebral palsy. A ventriculo-amniotic shunt can be placed into the fetal brain to allow the fetal brain to drain properly. Clewell and Johnson, A Surgical Approach to the Treatment of Fetal Hydrocephalus, 306 New Eng. J. Med. 1320 (1982). See generally Murray, Ethical Issues in Fetal Surgery, 70 Am. Coll. of Surg. Bull 6 (1985); J. Robertson, The Right to Procreate and In-Utero Therapy, 3 J. of Med. 333 (1982).

254. Roe v. Wade, 410 U.S. at 163.

255. 439 U.S. 379 (1979).

256. Id. at 400. See also American College of Obstetricians and Gynecologists v. Thornburgh, 737 F.2d 283 (3rd Cir. 1984) aff'd 106 S.Ct. 210 (1986).

257. I conducted a survey of all Army and Air Force medical centers. The Navy no longer designates any hospital as a medical center. Ms. Janet Jackson, Naval Medical Command, Bethesda, Maryland, provided names of the five largest navy hospitals which provide obstetric care. I surveyed the points of contact listed at Appendix A in Feb. and Mar. 1987.

258. See Andrews Air Force Base Medical Center and Eisenhower Army Medical Center at Appendix A.

259. See Appendix A.

260. See supra note 206.

261. See Tripler Army Medical Center, Eisenhower Army Medical Center,
and Wright Patterson Medical Center at Appendix A.

262. Williams Obstetrics, at 807.

APPENDIX A

Army Medical Centers	Brooke A.M.C. San Antonio, Texas	William Beaumont A.M.C. El Paso, Texas
Point of Contact:	Dr. (Maj) Arthur Schipul	Dr. (Col) James Brown
Need for Genetic Counseling Documented In	History and Physical	History and Physical
Criteria for Genetic Counseling	AMA Standards	AMA Standards
Patients Requiring Counseling Referred To:	Staff Perinatologist with assistance from staff geneticist	Staff Perinatologist
Diagnostic Tests Used	Amniocentesis/Ultrasound	Amniocentesis/Ultrasound
Chorionic Villi Sampling/Fetoscopy Referrals to Civilian Hospitals	1 patient for CVS	None
Alphafetoprotein (AFP) Screening Offered	To all patients	To all patients
Problem Areas:	Expansion in counseling workload due to AIDS/AFP	Lab specimens for AFP/ Amniocentesis takes too long at civilian laboratories

Army Medical Centers	Eisenhower A.M.C. Augusta, Georgia	Fitzsimmons A.M.C. Denver, Colorado
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Point of Contact:	Dr. (Maj) Larry Decker	Dr. (Col) Richard Jones
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Need for Genetic Counseling Documented In	History and Physical	History and Physical
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Criteria for Genetic Counseling	AMA Standards	AMA Standards
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Patients Requiring Counseling Referred To:	Medical College of Georgia for genetic counseling	Staff Perinatologist
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Diagnostic Tests Used	Amniocentesis/Ultrasound	Amniocentesis/Ultrasound
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Chorionic Villi Sampling/Fetoscopy Referrals to Civilian Hospitals	None	1 patient for CVS
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Alphafetoprotein (AFP) Screening Offered	Not offered to any patients No plans for AFP in future	To all patients
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Problem Areas:	AFP screening has expanded genetic counseling workload.
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**Army Medical
Centers****Letterman A.M.C.
San Francisco, California****Madigan A.M.C.
Tacoma, Washington**

Point of Contact:

Dr. (Ltc) Joseph Zimmerman

Dr. (Col) John Read

Need for Genetic
Counseling
Documented In

History and Physical

History and Physical

Criteria for
Genetic Counseling

AMA Standards

AMA Standards

Patients Requiring
Counseling Referred
To:

Staff Perinatologist

Staff Perinatologist

Diagnostic Tests
Used

Amniocentesis/Ultrasound

Amniocentesis/Ultrasound

Chorionic Villi
Sampling/Fetoscopy
Referrals to
Civilian Hospitals

1 patient for CVS

None

Alphafetoprotein
(AFP) Screening
Offered
Problem Areas:

To all patients

Presently offered to 30-35
year olds. Will be offered
to all when funds available.
Expansion in workload due
to AFP/AIDS. More
counselors needed.

**Army Medical
Centers**

**Tripler A.M.C.
Honolulu, Hawaii****Walter Reed A.M.C.
Washington, D.C.**

Point of Contact:

Dr. (Maj) Mark Copelman

Dr. (Col) Anthony Ambrose

Need for Genetic
Counseling
Documented In

History and Physical

History and Physical

Criteria for
Genetic Counseling

AMA Standards

AMA Standards

Patients Requiring
Counseling Referred
To:

Staff Perinatologist

Staff Perinatologist

Diagnostic Tests
Used

Amniocentesis/Ultrasound

Amniocentesis/Ultrasound

Chorionic Villi
Sampling/Fetoscopy
Referrals to
Civilian Hospitals

None

1 patient for CVS

Alphafetoprotein
(AFP) Screening
OfferedOffered to high risk
patients only.Will be offered to
all patients

Problem Areas:

Expansion in workload.

**Air Force
Medical Centers**

**Malcolm Grow M.C.
Camp Springs, Maryland****David Grant M.C.
Fairfield, California**

Point of Contact:

Dr. (Maj) Philip Urso

Dr. (Col) Larry Dennis

Need for Genetic
Counseling
Documented In

History and Physical

History and Physical

Criteria for
Genetic Counseling

AMA Standards

AMA Standards

Patients Requiring
Counseling Referred
To:

Referred to Bethesda Navy
Medical Center

Staff Perinatologist

Diagnostic Tests
Used

Amniocentesis/Ultrasound
(referred to Johns Hopkins
for level 2 Ultrasound)

Amniocentesis/Ultrasound

Chorionic Villi
Sampling/Fetoscopy
Referrals to
Civilian Hospitals

None

None

Alphafetoprotein
(AFP) Screening
Offered

To all patients

To all patients

Problem Areas:

**Air Force
Medical Centers**

**Kessler M.C.
Biloxi, Mississippi****Wilford Hall M.C.
San Antonio, Texas**

Point of Contact:

Dr. (Maj) Alan Bombard

Dr. (Cpt) Cindy Reynolds

Need for Genetic
Counseling
Documented In

History and Physical

History and Physical

Criteria for
Genetic Counseling

AMA Standards

AMA Standards

Patients Requiring
Counseling Referred
To:

Kessler is designated the
USAF Medical Genetics Counseling
Center with 2 MD Geneticists,
2 Ph.D. Geneticists, and a Nurse
Geneticist.

Staff Perinatologist

Diagnostic Tests
Used

Amniocentesis/Ultrasound

Amniocentesis/Ultrasound

Chorionic Villi
Sampling/Fetoscopy
Referrals to
Civilian Hospitals

Several referred for CVS

None

Alphafetoprotein
(AFP) Screening
Offered

To all patients

To all patients

Problem Areas:

**Air Force
Medical Centers**

**Wright Patterson M.C.
Dayton, Ohio**

Point of Contact: Dr. (Col) Louis Battino

Need for Genetic
Counseling
Documented In History and Physical

Criteria for
Genetic Counseling AMA Standards

Patients Requiring
Counseling Referred
To: Staff Perinatologist

Diagnostic Tests
Used Amniocentesis/Ultrasound

Chorionic Villi
Sampling/Fetoscopy
Referrals to
Civilian Hospitals None

Alphafetoprotein
(AFP) Screening
Offered Not offered to any patients

Problem Areas:

**Navy Medical
Centers**

**Balboa Naval Hospital
San Diego, California****Bethesda Naval Hospital
Bethesda, Maryland**

Point of Contact:

Dr. (Cdr) Tom Moore

Dr. (Cdr) Ipsath Hoskins

Need for Genetic
Counseling
Documented In

History and Physical

History and Physical

Criteria for
Genetic Counseling

AMA Standards

AMA Standards

Patients Requiring
Counseling Referred
To:

Staff Perinatologist

Staff Perinatologist and
Multi-disciplinary Review
BoardDiagnostic Tests
Used

Amniocentesis/Ultrasound

Amniocentesis/Ultrasound

Chorionic Villi
Sampling/Fetoscopy
Referrals to
Civilian Hospitals4/5 patients per year for CVS
Patients reimbursed by CHAMPUS

None

Alphafetoprotein
(AFP) Screening
Offered

To all patients

To all patients

Problem Areas:

Navy Medical Centers	Charleston Naval Hospital Charleston, South Carolina	Oakland Naval Hospital Oakland, California
Point of Contact:	Dr. (Cdr) La Floyd Hobbs	Dr. (Cdr) Robin Field
Need for Genetic Counseling Documented In	History and Physical	History and Physical
Criteria for Genetic Counseling	AMA Standards	AMA Standards
Patients Requiring Counseling Referred To:	Medical University of South Carolina	Staff Perinatologist
Diagnostic Tests Used	Amniocentesis/Ultrasound	Amniocentesis/Ultrasound
Chorionic Villi Sampling/Fetoscopy Referrals to Civilian Hospitals	None	1 patient for CVS. Patient paid for procedure herself.
Alphafetoprotein (AFP) Screening Offered	To all patients	To all patients
Problem Areas:		Lab at Letterman Army Medical Center does not provide AFP test values for Down's Syndrome.

**Navy Medical
Centers**

**Portsmouth Naval Hospital
Portsmouth, Virginia**

Point of Contact:	Dr. (Cdr) Wayne Hess
Need for Genetic Counseling Documented In	History and Physical
Criteria for Genetic Counseling	AMA Standards
Patients Requiring Counseling Referred To:	Staff Perinatologist
Diagnostic Tests Used	Amniocentesis/Ultrasound
Chorionic Villi Sampling/Fetoscopy Referrals to Civilian Hospitals	Several patients for CVS. Hospital paid for it.
Alphafetoprotein (AFP) Screening Offered	To all patients
Problem Areas:	Due to increased workload, genetic counseling will be contracted to East VA Medical College

APPENDIX B

	Circle Appropriate Answer	
1. Will you be age 35 or older when the baby is due?	YES	NO
2. Have you or the baby's father or anyone in either of your families ever had:		
a. Down syndrome or mongolism?	YES	NO
b. Spina bifida or meningomyelocele (open spine)?	YES	NO
c. Hemophilia (blood won't clot)?	YES	NO
d. Musclar dystrophy?	YES	NO
3. Have you or the baby's father had a child born dead or alive with a birth defect not listed in Question 2 above?	YES	NO
If Yes, describe:		
4. Do you or the baby's father have any close relatives who are mentally retarded?	YES	NO
If Yes, list cause if known:		
5. Do you or the baby's father or close relative in either of your families have any inherited inherited genetic or chromosomal disease or disorder not listed above?	YES	NO
6. Have you or the spouse of this baby's father in a previous marriage, had three or more <u>spontaneous</u> pregnancy losses?	YES	NO
7. Do you or the baby's father have any close relatives descended from Jewish people who lived in Eastern Europe (Ashkenazic Jews)?	YES	NO
If Yes, have either you or the baby's father been screened for Tay-Sachs disease?	YES	NO
If Yes, indicate results and who screened:		

8. If patient or her spouse is black -
Have you or the baby's father or any close
relative been screened for sickle cell
trait and found to be positive?

YES

NO

I have discussed with my doctor the above questions where are answered
"YES" and understand that I am at increased risk for _____,
and that it is usually possible to diagnose an affected fetus by testing
amniotic fluid at about 16 weeks of pregnancy and I DO NOT want the test.

(Patient Signature) (Date)

I have discussed alpha-fetoprotein screening with my doctor and I DO NOT
want the test.

(Patient Signature) (Date)

Patient wants amniocentesis and fetal diagnoses for: _____

Patient wants alpha-fetoprotein screening: _____

Patient referred for further testing or counseling concerning:
